Spousal Identity Stage Theory in Dementia Caregiving

A Bittersweet Journey

A Dissertation Presented

by

Carolyn Marie Gallogly

to

The Graduate School

in Partial Fulfillment of the

Requirements

for the Degree of

Doctor of Philosophy

in

Social Welfare

Stony Brook University

May 2008

Stony Brook University

The Graduate School

Carolyn Marie Gallogly

We, the dissertation committee for the above candidate for the

Doctor of Philosophy degree, hereby recommend

acceptance of this dissertation.

Harvey A. Farberman, Ph.D. – Dissertation Advisor
Professor, School of Social Welfare

Richard H. Morgan, Ph.D. – Chairperson of Defense
Clinical Assistant Professor, School of Social Welfare

Angel Campos, Ed.D.
Associate Professor, School of Social Welfare

Christopher L. Hayes, Ph.D.
Gerontology, Long Island University (Retired)

This dissertation is accepted by the Graduate School

Lawrence Martin
Dean of the Graduate School

Abstract of the Dissertation

Spousal Identity Stage Theory in Dementia Caregiving

A Bittersweet Journey

by

Carolyn Marie Gallogly
Doctor of Philosophy
in
Social Welfare
Stony Brook University

2008

This qualitative study into the identity issues facing spousal caregivers of persons with a perceived cognitive deficit, grew out of the studies conducted by Farberman, Finch, Horowitz, & Lurie (2001) and Farberman, Finch, Lurie, & Morgan (2003). These two studies showed that the period of peak burden for caregivers occurred during the middle stages of caregiving, when there was a shift from Instrumental Activities of Daily Living (IADL) support to Activities of Daily Living (ADL) support. The increased burden was greatest for spousal caregivers of those with dementia. The question is why? Although much research has been done on the general subject of burden, this study approaches the issue of burden with the lens of spousal social identity.

Using grounded theory methods, 40 spousal caregivers were interviewed, the majority of whom were white females (although 11 were male, and 3 were non-white)**.**

A purposive sampling technique was used and recruitment of respondents took place at Alzheimer's support groups, adult day care centers, and other relevant sources. The interview guide evolved as new information emerged, with interviews averaging 1 ½ hours.

The results showed a distinct change in the caregivers' perceptions of their own identities, as well as their care receivers' identities. This change often occurred simultaneous with a specific event that dramatized the care receivers' lack of mastery with resulting increased dependency. The conceptualization of the couple's identity, as a symbiotic pair, borrowing the direct meaning of the metaphor of symbiosis from biology, is central to the findings. The data from the interviews pushed in the direction of a stage theory, and indeed all of the caregiving couples, with one exception, were moving through the proposed stages, based on types of symbiosis.

The grounded theory arising from this research points out that the spousal relationship intensifies during the caregiving experience, thus clarifying *why* spousal caregivers often become overwhelmed by various sources of stress, and *when* intervening mediators should be attempted in order to support both care receiver and caregiver.

Dedication

This research project is dedicated to my mother, Marcella Gallogly, who not only lived the journey of the dementia caregiver spouse, but serves as my constant model of loving commitment to *him, from whom much was taken.* She never wavered in her loving care. Although the disease could not be vanquished, together, they vanquished the fear.

CONTENTS

Types of Stressful Medical Interactions for Caregiver

APPENDICES

LIST OF TABLES

Acknowledgements

This study would not have been successful without the support and encouragement of many people. First of all, I would like to thank Professor Harvey A. Farberman, my mentor for the past 8 years, and my dissertation sponsor for the past 4 years. Dr. Farberman included me in meetings of the Center for Aging Policy Research of the School of Social Welfare, and by so doing laid the ground work for the question which drove this study. Also supportive of my scholarship have been other Social Welfare faculty during the past 5 years: Ruth Brandwein, Angel Campos, Abe Lurie, Richard Morgan, and Charles Robbins. I would be remiss if I did not include in this same group, my doctoral student cohort and friends, who always gave support when it was sought. Edie Lundgren, Administrative Assistant for the Doctoral Program, has been the key linchpin in my journey since the first day.

Finding 40 spousal caregivers who would be willing to spend an hour or two pouring out their soul-felt observations about what was happening to them during their spouse's battle with dementia, would not have been possible without the direct support of Darlene Jyringi, Program Director of the Alzheimer's Disease Assistance Center of Long Island, as well as personal friends and professional contacts in the Gerontology Professionals of Long Island.

I also thank my employer, St. Joseph's College, and my Dean, Tom Travis, for believing in me, and encouraging me along the way. Furthermore, without a true transcriptionist and friend, Christina Martin, I might possibly have never reached the analysis stage! Finally, I could not have finished the dissertation without the consistent inspiration, understanding, and cooperation of my family, Andy, Molly, and most significantly, my spouse, Bob Bright.

CHAPTER 1: INTRODUCTION AND REVIEW OF THE LITERATURE

In the same years that public consciousness has been stimulated by images of vast numbers of baby boomers growing older, the subject of caregiving also has grown in significance. With so many individuals facing several decades of encroaching frailty and/or dependency, it is no wonder that public and private attention is focused on *who* will provide the needed care. At the same time as the number of frail elders is increasing, the Health Resources and Services Administration (HRSA) has echoed the concerns of others regarding shortages of the nursing aides and home health aides, the direct care workers who typically would provide the formal care. HRSA (2004) projects that the supply of these workers, typically women between 25 and 50, has been unable to keep up with the demand, and will continue to fall well into the future.

Background and Demography of Family Caregiving

Thus, formal caregiving by home health aides is unlikely to keep pace with the demand for in-home caregiving, and, consequently, informal caregiving, as provided by family members and friends, will continue to be the major source of care to frail elders. This is not new. As Tennstedt (1999) framed it in her report for the National Institute on Aging, caregivers always have come from the families of the elders and will continue to do so. Research has been studying family caregiving for many decades, sometimes focusing more on adult children and the challenges inherent in that relationship, and sometimes, focusing on the unique issues confronting spousal caregivers. There also have been very specific bodies of research that have attempted to define who is providing the care, as well as producing demographic data that describes the caregiving experience.

The American Association of Retired Professionals (AARP) commissioned three telephone survey studies of caregiving in the United States: the first with The Travelers Foundation (1987); then in conjunction with the National Alliance for Caregiving (1997);

and most recently, again, with the National Alliance for Caregiving (2004) (Wagner, 1997; National Alliance for Caregiving, 2005). These national surveys set a standard of caregiving research, which New York State used in the 2001 telephone survey, **Informal, Unpaid Care Giving to New York State Elders** (Farberman, Finch, Horowitz, & Lurie). Farberman et al. of the Center for Aging Policy Research at Stony Brook University used the random digit dialing telephone survey method to get a snapshot of informal, unpaid caregiving by any individual, within a household, over 18 years old for someone over 60 years old. The most affecting part of that research concerned the care of those elders who were at higher stages of caregiving need. When caregiving required assistance with all of the Activities of Daily Living (ADLs), including bathing, mobility, transfer, dressing, eating, medication administration, personal hygiene, and toileting, informal caregivers were putting in an average of 88 hours of care each week (Farberman et al., p.3).

Statement of the Research Question

In the follow-up **Survey of Family Care Giving to Elders in Suffolk County, New York: 2003** (Farberman, Finch, Huddy, Lewis, Lurie, & Morgan), a shortened version of the Zarit Burden Scale was added to the telephone interview (Bedard, Molloy, Dubois, Lever, O’Donnell, 2001; O’Rourke, N. & Tuokko, H. A., 2003). The Zarit Burden Scale is normally a 22 question Likert scale interview, designed to show level of subjective burden in caregivers, devised by Steven Zarit (Zarit, S. H., Orr, N. K., & Zarit, J. M., 1985). With the addition of the “screening” short version of the Zarit Burden Scale, the second telephone survey was able to look at burden as it related to level of care. The results indicated that caregivers in Suffolk County for elders were at highest burden in Level 3 caregiving intensity, when one ADL was required in the caregiving. What marks the difference between an Instrumental Activity of Daily Living (IADL) and an Activity of Daily Living (ADL) is the physical and personal nature of the help provided. Rather than merely assisting with paying bills or providing transportation, helping with an ADL means that the caregiver must actually get physically involved with the care receiver, assisting with dressing, bathing, toileting, or other personal care tasks.

Something about this new demand on the caregiver triggers a high level of burden, the most burden voiced by caregivers at any of the earlier or later stages of caregiving. Addressing the question of why assisting with an Activity of Daily Living (ADL) would trigger this high level of burden became the starting point for an exploratory qualitative study to take shape.

Additionally, because the Suffolk study (Farberman et al., 2003) revealed that spousal caregivers, as well as dementia caregivers, showed the highest levels of burden, focusing on this population might help describe why these caregivers are more susceptible to caregiver burden, and in doing so, perhaps support policy initiatives targeting this group. Thus, the purpose of this dissertation focuses on spousal caregivers of those with a perceived cognitive impairment. It is an exploratory study that will try to address the emerging questions about identity and roles during Level 3 of spousal dementia caregiving, the point at which spousal caregivers are just beginning to perform an ADL for their partners. Perhaps uncovering the dynamic of potentially shifting roles and identities will explain the earlier findings concerning burden.

Caregiving and Dementia

Although this study does not focus on changes in the dementia care receiver, the "unbecoming of the self," i.e. the unraveling of the cognitive identity in those with dementia, is balanced with "normalization procedures" practiced by the caregiver for the person with dementia (Fontana and Smith, 1989). These supportive behaviors help maintain the dementia care receiver as a social being, and carry on with the routines of daily life. The caregiver thus continues to have some sort of control over what is happening to the care receiver.

Dementia caregiving will be the major focus of this study, so research that suggests issues specific to dementia caregiving is relevant. However, as Ory, Yee, and Tennstedt (2000) emphasized, one should not generalize from studies of dementia caregivers to non-dementia caregivers and vice versa. There are too many differences between the experiences of the two groups and the results would be misleading.

The Alzheimer's Association and the National Alliance for Caregiving (NAC) (2004) published a report on dementia caregiving which states that, five million American families are caring for a loved one with dementia. Dementia caregivers were shown in this study to be more likely to provide over forty hours of care each week; to have been providing care for at least one year, with 38% providing care for more than five years; to provide help with more ADLs; to be dealing with incontinence; to be co-residing with the care receiver; to be reporting more physical strain and emotional stress; and to be providing most of the care by themselves. This portrait of dementia caregiving shows why such caregiving should not be generalized to all caregivers. These factors show larger and more intense expenditures of effort and time.

The Alzheimer's Association/NAC survey interviewed various family members and friends. Approximately 10% of the caregivers were a non-relative or friend, 42% were adult children caring for a mother, father, grandparent, parent-in-law, aunt or uncle, and 9% spousal caregivers. Thus, when doing the randomized telephone survey of caregivers, the percentage of spousal caregivers was lower, but it was exactly that part of the sample that indicated the most intense caregiving situations. They were more likely to co-reside, and experience the more extreme demands of caregiving for longer hours (p. 8).

Recalling that the Zarit Burden Scale (Zarit et al., 1985; Zarit, Reever, & Bach-Peterson, 1980) is a major tool in the estimate of psychological strain related to the special demands of dementia caregiving, most of the studies include the measure. Anthony-Bergstone, Zarit, and Gatz (1988) pointed out that caregiving was not only related to burden but also to a weakening of mental health. They found hostility and anxiety frequently in caregivers, and depression more often in older female caregivers. The mean length of duration for the disease, in this study, was 8.25 years.

Schulz, O'Brien, Bookwala, & Fleissner (1995) did a review of dementia caregiving research from 1989-1995 and saw strong evidence for the relationship between psychiatric effects and dementia caregiving, including higher levels of depressive symptoms, and when diagnostic interviews were part of the methodology, higher levels of clinical depression and anxiety. The review went on to target specific causes for the psychiatric problems. Those causes included dementia care receiver problem behaviors, the decline and impending death of the loved one, and a concept called “contagion,” defined as catching the mood of the dementia care receiver (pp.787-788).

There is much research that explores causes or factors within the dementia caregiving experience that lead to caregiver stress, distress, and possible depression. Kosloski, Young, and Montgomery (1999) linked behavior problems of the care receiver to the distress of the caregiver. Their study used data from 573 dementia caregivers and looked specifically at the expectations of the caregiver to provide care as a factor related to caregiver depression. Although they found that caregiver social expectations related to the caregiver level of depression, they also found that the physical health of the caregiver and the problem behaviors of the care receiver had a stronger relationship to depression.

That finding about problem behaviors is significant for it is a part of the disease of Alzheimer’s that does not remain steady during the disease progression. Haley and Pardo (1989) first pointed out that the experience of the problem behaviors was not linear, and rather peaked in the middle stages of the disease, about the same time as the ADLs require more attention from the caregiver. The functional needs of the care receiver continued to grow, but the behavior issues actually receded. Thus, if depression is so strongly related to problem behaviors, we can expect to see it emerge in the middle stages, and not necessarily be a major factor in the late stages.

Alspaugh, Stephens, Townsend, Zarit, and Greene (1999) tackled the issue of care receiver problem behaviors in interviews with a 188 person sample of caregivers over a three year period, thus providing longitudinal data. The dementia caregivers who also were spouses showed stress related to increases in problem behaviors over time, perhaps due to their closer, more sustained contact with the care receiver. The research also found that ADL dependencies and problem behaviors were predictors for role overload, with the problem behaviors also related to emotional problems for the care receiver. This study, however, did not address the research which showed the non-linear aspect of the problem behaviors.

Two related studies came out of the large research project titled the Canadian Study of Health and Aging, which sampled Canadians over 65 during a ten year period. The first was Meshefedjian, McCusker, Bellavance and Baumgarten (1998) who looked at informal caregivers (n=321) of dementia care receivers. Their multiple regression analysis found that depression scores on the Center for Epidemiologic Studies Depression Scale (CES-D), the same scale used by Koslowski et al. (1999), were associated with older caregivers, less educated caregivers, unemployed caregivers, spousal caregivers, co- residents with the care receiver, and, finally, those who did not identify themselves as either English or French. Another predictor of depression, as we saw in the other studies, was "greater behavioral disturbance and greater functional or cognitive impairment" (p. 249).

The Canadian Study of Health and Aging Working Group (2002, no specified author) produced longitudinal data at the end of ten years, and published findings showing what happened over time to the 948 informal caregivers, who were interviewed in 1991 and 1996. Caregivers still providing care in the community, at the time of the second interview, showed greater burden on the Zarit scale than those whose care receiver had gone into an institution. Caregivers for the very frail and/or dementia care receivers showed depression level scores on the CES-D noted above.

Hooker, Bowman, Coelho, Lim, Kaye, Guariglia, and Li, (2002) used 64 cases of dementia caregiver/care receiver dyads to see if behavioral changes *over time* in the care receiver were linked to caregiver mental or physical health changes. They found that weakening mental and physical health for the caregiver was associated with the degree of increase in problem behaviors of the care receivers.

Related to studies on caregiver depression and the associated factors of care receiver problem behaviors and functional decline, Powers, Gallagher-Thompson, and Kraemer (2002) examined the coping behaviors of the caregiver, finding that those behaviors tended to remain stable, during the caregiving experience. They interviewed 51 caregivers of dementia care receivers, four times, with 6 months between each interview. This was a more positive finding, amidst so much research that reported burden, depression, and stress.

Caregiving and the Marital Relationship

The other significant variable in the Suffolk Caregiver Study (Farberman et al., 2003) was the spousal relationship between the caregiver and care receiver as a factor related to higher level of burden in the middle stages of caregiving. Most studies of spousal caregiving focus on heterosexual couples, but clearly the experience of gay couples in later life would include the same challenges if one partner developed dementia. A review of spousal caregiver studies shows a number of relevant findings.

Approaching the caregiving experience from a couple perspective seems to have become a more significant question in the last ten years, as the word “dyad” started to show up in the titles of the research. This change in emphasis merely brings attention to what seems increasingly obvious in the field. There is something linking caregiver and care receiver and the quality of that link is an important part of the caregiving equation. By using the work “quality”, one does not assume that the relationship is necessarily a happy one, but that it is a strong one. According to Lyons, Zarit, Sayer, and Whitlatch (2002), the quality of the caregiving relationship includes the factors of cohesion, satisfaction, tension, and conflict. Lyons et al. looked at dyadic conflict, what they defined as the end result of the **incongruency** of the goals and perspectives of the caregiving dyad. When there was “relationship strain”, an indicator of a poor relationship quality, disagreement between caregiver and care receiver about caregiving difficulties was more likely. Perhaps even more helpful than the results of the study, which almost seem to be common sense, was the recommendation that therapeutic interventions should include targeting the caregiving relationship in order to prevent some of the disagreement over the caregiving experience and the resulting strain (p. 203).

Another study that looked at the marital relationship as a significant factor in the dementia caregiving experience was Baikie’s (2002) qualitative study of the effect of dementia on marital relationships. The findings are based primarily on interviews, although Baikie doesn’t include specific information on methods, but the narrative is still interesting because it addresses topics often neglected in caregiving research. For example, there is a focus on anticipatory grief and how caregivers sometimes come to see their spouses as already dead, that is, socially dead. This concept of “social death” is well developed by Sweeting and Gilhooly (1997) in the introduction to their research on the effect of believing someone is “already dead” though biologically still alive. They interviewed 100 subjects, who had a family member with dementia, and of those, 50 were spouses. The resulting qualitative analysis pointed out that the majority made comments showing that they believed their care receiver was to some extent socially dead, but they, the caregivers, still behaved toward them as if he or she were alive. However, one third of the sample believed the care receiver was socially dead and treated them that way. In their study, that treatment primarily meant wishing for the physical death of the person with dementia, no longer worrying about the person’s social appearance and behaviors, starting to withdraw from them emotionally.

Baikie (2002) also addressed sexuality and dementia, but mainly with questions. There is almost no research on this topic, other than to suggest that males, who suffer from dementia, may show increased sex drive possibly owing to disinhibition. Females with dementia might show an increase or a decrease in sexual behaviors, very much like the male. However, other than hypothesizing about sexuality, there is little evidence to back up anyone’s opinion.

J. Zarit (2001) wrote of clinical experience with dementia couples who continue to be sexually active, although one of them is experiencing cognitive losses. Affectionate behaviors tend to be calming to dementia spouses and a long and satisfying relationship prior to the dementia appear to be associated with this continued sexuality.

Gallagher-Thompson, Dal Canto, Jacob and Thompson (2001) looked specifically at interactions in marriages where the husband had Alzheimer’s disease. This research team included video data, showing interactions at the dining table, which were coded using a tested standard, the Marital Interaction Coding System. Because both dementia couples and non-dementia couples participated, results could be compared. Non-dementia couples had more interactions, probably owing to the expected slowing down in communication skills for dementia spouses. Communication was more simplified for dementia couples. Caregiving wives were less supportive of their husband’s ideas, than were the non-caregiving wives. Most of the caregiver wives’ time was spent solving problems and clarifying topics. Dementia husbands took turns speaking, but used fewer words, and didn't show any ability to contribute to the topic. However, dementia spouses did show a facility for using humor, especially when commenting on their inability to respond to something asked of them. Clearly this type of research is labor intensive, but it does open up aspects of the couple relationship which remain relatively unexplored. The authors proposed that more interventions be based on helping the caregiver handle these chronic stresses, and develop more skills to meet communication challenges (p.149).

Another study directed at the question of how dementia caregiver spouses remain committed to their role as caregiver was conducted by LoboPrabhu, Molinari, Arlinghaus, Barr, and Lomax (2005). This team combined three separate constructs in an effort to understand this marital bond: the concept of delayed *quid pro quo* where reciprocity is accepted because the dementia spouse was responsible and productive during earlier years; the concept of commitment and family solidarity; and the concept of holding on, because letting go is not acceptable. These authors also saw the dementia challenge as the experience of the caregiver spouse to keep trying to fix the severed bond of the marriage, which ultimately was irreparable. These ways of viewing the dementia dyad are very helpful in seeing into the motivations of the caregiver spouse. Their study was more an exploration of how various theories of marital relationships apply to the dementia situation, and by this exploration, they made recommendations on how professionals might support the caregiver efforts at maintaining the marriage. They also emphasized the value of professional support for the sexual aspects of the relationship, of not being afraid to address the topic, and, for allowing the caregiver to discuss his or her concerns.

Kim and Keshian (1994) reviewed nursing case studies that showed a trend toward more old-old caregiver spouses where frailty is present for both caregiver and care receiver. They emphasized that the hallmark of this type of caregiving situation was the long term relationship between caregiver and care receiver, where the caregiver spouse showed notable strength, commitment, and devotion. They also observed that the caregiver often does not reach out for help.

Another interesting and unique paper by Arai, Zarit, Sugiura, and Washio (2002), focused on caregiving in rural Japan. Their findings were based on a longitudinal study over one year's time, involving 47 pairs of caregivers and care receivers. Caregiving for someone with dementia was five times more likely to lead to a negative effect on well-being and increased burden; however, if the caregiver was the spouse, the adaptation was five times more successful, and if a daughter-in-law, the result more likely would be unsuccessful, suggesting again that there is something about the "quality" or strength of the relationship between the caregiver and care receiver that supports caregiver well being and adaptation to the demands.

An earlier publication by Kramer (1993) dealt with dementia caregiver wives, and emphasized coping strategies that were relationship-focused, rather than problem-focused or emotion-focused. Kramer stated that so little research has been directed at helping the caregiver maintain the relationship, thus neglecting a more positive approach to supporting dementia couples. Whitlatch, Judge, Zarit, and Femia (2006) followed through on this tactic to view dementia caregiving as a relationship-based experience with an intervention aimed specifically at the caregiving dyad, rather than the individual caregiver. The intervention was focused on early diagnosed dementia patients, making the care receiver more active in creating a care plan; strengthening the communication pattern between caregiver and care receiver; increasing information about services available; and supporting the dyad through the transitional period. The intervention was well received and accepted, most successful with spouses, and less successful when the caregiver was a younger family member.

Caregiving Stages and Transitions

Having looked at research on couples challenged by dementia, it seems appropriate to visit the literature on stages of caregiving and the (theorized) transitions in caregiving. Perhaps the earliest attempt to apply such a framework to dementia caregiving was by Montgomery and Kosloski (2000). They viewed caregiving as a dynamic process, where there is great variability in the trajectory, which depends on the level of the impairment, whether there is stability in the functionality of the care receiver, and the physical and social environment of the caregiving experience. They theorized that there are stages of caregiving and based their framework on **marker events**. The marker events chosen by Montgomery and Kosloski included performing caregiver tasks; defining oneself as a caregiver; providing personal care; seeking assistance or formal services; considering nursing home placement; institutionalizing the care receiver; and terminating the caregiver role.

What makes this framework most useful, whether or not one accepts the conceptual framework of stages, is the authors' suggestion that interventions be tagged to the stages. Furthermore, the last stage is not institutionalization, but rather the termination of the role, either because the care receiver dies, recovers, or the caregiver ceases to provide any care, including visiting the nursing home. The major weakness is that it clearly denotes institutionalization as an expected step. There are alternative possibilities for the dementia experience and by making institutionalization a key event, (even if everyone doesn't get to that step), creates an expected outcome that is viewed as undesirable by most adults. A downward trajectory is emphasized, leading to negative appraisals of caregiving. Nevertheless, to be fair, caregiving for someone with dementia, does involve a downward trajectory.

This is the only framework found that had more than three stages of caregiving. The remaining discussions of the caregiving experience typically concerned three events: entry into caregiving status, institutionalization, and bereavement. Seltzer and Li (2000) utilized these three stages in their large study of caregiving women whom they compared to non-caregiver wives or daughters with a loved one older than 60 who did not need care. They began the study with 129 caregiver wives; 207 caregiver daughters; 119 non-caregiver wives; and 86 non-caregiver daughters. Eighty-eight percent of the sample continued throughout the entire, 3-wave study.

Their findings used the three transition events to chart the course of caregiving, and then looked at other changes experienced by the caregivers and non-caregivers in the three waves. Of great interest is what else was happening to caregiver wives. Seltzer and Li found that their participation in leisure and social activities declined, a fact not seen in the non-caregiver wives. Also, during the three years of the study, not one wife placed her spouse in an institution, whereas 10% of the daughters did. On every measure of well being, the caregiver wives fell below the scores of the non-caregiver wives. Generally, this study supported the view that, following the death of the care receiver, the caregiver wives showed resilience, the ability of the caregiver to ultimately rebound from the burden of that experience.

Burton, Zdaniuk, Schulz, Jackson, and Hirsch (2003) also compared caregiver couples to non-caregiver couples over a five year period, using a large national prospective cardiovascular study. They divided the stages into non-caregiving, moderate caregiving, and heavy caregiving. There were four interviews, during the five year period, with the research focus on changes in the health of the caregivers over time. The caregivers who moved from moderate caregiving (providing one IADL to care receiver) to heavy caregiving showed the most depressive symptoms; heavy caregivers also showed the most health risk behaviors between the second and third interview. They did not find that self mastery fluctuated over time. They did see health risk, however, for spouses who entered heavy caregiving.

In the same year, Gaugler, Zarit, and Pearlin (2003) published an excellent article which looked at dementia caregiving, rather than caregiving in general, as with Burton et al. This study, once again, referred to the framework of the three types of transitions: entry into caregiver role, institutionalization, and bereavement. In this article, they focused on entry into the role, using secondary data from the Caregiver Stress and Coping Study (Aneshensel, Pearlin, Mullan, Zarit, and Whitlach, 1995). Although limited to dementia caregiving, the study included spousal and filial caregivers. The study lasted three years, and the caregivers were interviewed each year for as long as they remained in the study. By the time of the interview at the end of year three, the number of caregivers declined from 526 to 290, with only 127 care receivers of the original 526 still residing in the community. Since the focus of Gaugler et al. was primarily on point of entry, they developed a framework that divided the group according to these four descriptors: recognition-diagnosis (the caregiver recognized the dementia before the diagnosis); diagnosis-dependent (caregivers recognized symptoms at the same time that they sought help or diagnosis); recognition-care (caregivers recognized the symptoms before or at the same time help was provided); care-provision (caregivers were already providing care before they recognized symptoms or had a diagnosis.) The longest transition, time-wise, into the caregiver role was for the group who showed recognition-care. They found from their research that caregivers who had the most abrupt transition into caregiving, in other words those who became caregivers at the time of diagnosis, were also the ones most likely to give up the caregiver role over time. Those who had provided care over a period of time, well before diagnosis, faced an easier transition. This study certainly does show the variation in how and when caregivers take on the role. One can assume that each stage of the caregiving trajectory is probably open to such complex analysis.

In an earlier article by Skaff, Pearlin, and Mullan (1996), dementia caregivers were evaluated for their mastery, or sense of personal control, denoted in this study as part of the self concept, something that may vary across the lifespan, but is still relevant throughout one's life. They specifically looked at how mastery changes as their subjects experience transitions in caregiving during a three year study. These researchers label the transitions: continuing care, placement, and bereavement, similar to the aforementioned: entry into caregiver role, institutionalization, and bereavement. Their sample included 456 participants over a three year period. In general, they found that the caregiver's sense of mastery was a somewhat stable resource, but continuing care did cause it to diminish, then regain what was lost as the care receiver is placed in an institution. At the final transition, bereavement, mastery rises.

Gaugler, Kane, and Newcomer (2007) recently published a study looking at resilience in dementia caregivers. Seltzer and Li (2000) have already suggested resilience post-bereavement. Resilience is successful functioning in the face of stressful challenges, or stress resistance. Gaugler et al. saw it as the ability of some caregivers to continue to meet the challenges of caregiving, while at the same time, they saw an increase in burden and even some symptoms of depression. They did find that low resilience individuals were more likely to institutionalize the care receiver, an important finding for planning interventions that might support those caregivers so that their dementia care receivers might remain in the community longer.

On a different note, but still looking at the caregiving experience as part of the life course, Kramer and Lambert (1999) looked specifically at the experience of caregiver husbands, using a large national sample, from the first (1987 to 1988) and second parts (1992 to 1994) of the National Survey of Families and Households (NSFH). They looked at husbands who entered caregiving in the five year period between the two samples, and compared them to a control group of non-caregiver husbands. As expected, performance of household chores went up for the husbands who began caregiving during the five year period. The caregiver spouses also indicated less emotional support during the interview, and less marital happiness. Finally, those caregiving husbands also showed reduced well-being, when compared to the non-caregiver husbands during the same time period.

Pillemer and Suitor (2000) published a chapter in a book dedicated to the topic of social integration, on the subject of dementia caregiving and its relationship to social integration and family support. They emphasized the **status transition** aspect of becoming a dementia caregiver, and how this is becoming a life-course transition, building on the study above. They saw caregiving as a status that occurs when adults assume the role. They viewed it as a status role because it has particular expectations in society, in much the same way as becoming a parent, getting a job, enrolling in a school for education, etc. By seeing it in that way, there were correlates that can be assumed about the change: less time spent with associates to whom they are not so similar now, increase of time with those to whom they are more similar. That experiential similarity meant there was more empathic sharing, increased reassurance that their attitudes and feelings were normal, and general acceptance. (Support groups would seem to be a primary example of this experiential similarity.) If the support is coming from someone with whom the caregiver is also similar to in age, social status, education, etc., the experience will be even more supportive. Pillemer and Suitor raised the point that there were gender differences regarding the effect of experiential similarity on individuals seeking and accepting emotional support. They hypothesized that there would be even more importance for men to have this experiential similarity. Their research, however, showed the opposite. Women benefit more from experiential similarity immediately after entering this status role.

There are three additional studies that concern markers or transitions of dementia caregiving. The first was by Balsis, Carpenter, and Storandt (2005) which found that there is a personality change in the care receiver that occurs early in the dementia disease, even before diagnosis. This is relevant to looking at the role of the diagnosis in the career of the caregiver. He or she has had warning signs, as a result of the care receiver's personality change. The second study by Savundranayagam, Hummert, and Montgomery (2005), looked at the effect of communication problems on caregiver burden. What is especially interesting is the description of the dementia as a communication disorder. Viewing communication problems as contributing to caregiver burden, in and of themselves, not just as one of a set of problem behaviors, the researchers saw as possibly helping to "clarify the influence of disease progression and problem behaviors on caregiver burden" (p. 49). This particular study viewed the communication breakdown as problematic for both caregiver and care receiver. In the care receiver, this breakdown may cause even more problem behaviors due to the care receiver's frustration. This then compounded the stress on the caregiver. This happened earlier in the disease path, not in the later stages, an important finding for plotting the course of the disease. Although Savundranayagam et al. did not link this topic to a particular stage of caregiving, they recommended further study on this.

The last study of relevance to the transitions or stages of caregiving, is by Gaugler, Kane, Kane (R), Clay, and Newcomer (2003). Using prospective data drawn from the 3-year Medicare Alzheimer's Disease Demonstration Evaluation (MADDE), this study looked at a large sample of dementia care receivers (n=3,944), who were residing in a home setting when the research began. The focus of the study was on what predictors led to institutionalization. They found that 80-year-old caregivers and older were more likely to institutionalize the care receivers; care recipients with more IADL impairments were institutionalized sooner; more problem behaviors predicted institutionalization; higher burden on the Zarit Burden Scale accelerated institutionalization; caregiver-perceived poor self-health led to institutionalization; care receivers who had low levels of home chore services were institutionalized sooner; and finally, care recipients who used *low or high* levels (as opposed to moderate levels) of adult day services were more likely to be institutionalized. The last two of these significant variables can also serve as signposts for predicting the caregiver may be facing the decision to institutionalize the care receiver.

Caregiving and Identity

The initial impetus to look more closely at caregivers and their challenges during the middle stages of caregiving when they are starting to help their care receivers with an activity of daily living, came from the sense that what might be going on involved identity issues, a topic not well addressed in most research about caregiving. The idea of changing identity as a cause of stress in the caregiver seemed rational, intriguing and perhaps useful to the strategists planning supportive interventions for dementia caregivers.

First, by identity, this study relies primarily on the tradition of William James, Charles Horton Cooley and Herbert Mead, whereby identity is linked to a social self. Although some definitions of identity focus on the individual as in a persisting set of qualities that uniquely define the individual, or on group membership and the shared qualities of that membership, for this study, identity is viewed as a social concept based on interactions. Everything about spousal caregiving implies a social role, a social interaction, not only with the care receiver spouse, but also with the larger family, the friendship circle, the neighbors, the professional service providers and so on. Thus, caregiver identity is tightly bound up with the symbolic interactionism, a self knowledge constantly being formed and reformed by reacting to how others act toward the caregiver, seem to perceive the caregiver, or Cooley's "looking-glass self."

Therefore, it is helpful to first review some of the social identity theory that might be applicable to caregiving. Social identity is rooted in the 1892 writings of William James, a pragmatist, who used personal pronouns to communicate the notion of self awareness: "I" is the source of the awareness, and "Me" is the object of the awareness. Thus, we are objects to ourselves, although he cautions against trying to separate the self (Holstein & Gubrium, 2000, p. 23). Although James further divided the self into a material self, a social self, and a spiritual self, he is best known for what he says about the social self. The self is what is formed from the process of social interaction. James said: "a man has as many social selves as there are individuals who recognize him and that carry an image of him in their minds" (p. 24).

Charles Horton Cooley followed William James in the development of social psychology theory, and his major contribution was the concept of the "looking-glass self." Cooley always saw the self in relation to others. He didn't believe we could see ourselves, examine ourselves, without seeing ourselves connected to others. "Self and other do not exist as mutually exclusive social facts…" (Cooley, 1983[1902], p. 126). He wrote of the social self, and James's "pronouns," and then went on to develop his theory of the "looking-glass self," something he referred to as a "somewhat definite imagination of how one's self. . . appears in a particular mind, and the kind of self-feeling one has is determined by the attitude toward this attributed to that other mind" (p. 183-184). The imagined judgment of the other regarding our "self" is what can lead to our shame or our pride. He said we are always imagining what the other is viewing as our "self." Certainly, spousal caregivers are challenged by this interaction. Does my spouse still know me? Does he/she still love me? Why does he/she have so much anger toward me?

The next contribution to social psychology came from George Herbert Mead (1934). His core concept was "self consciousness" rather than "self feeling" (Holstein and Gubrium, 2000, p. 27). He viewed communication as the way in which an individual can "become an object to himself" (Mead, 1962 [1934], p. 138). Mead introduced the term "interaction" and saw the interactions between individuals as the origins of the self. "It is the social process itself that is responsible for the appearance of the self; it is not there as a self apart from this type of experience" (p. 142). According to Holstein and Gubrium (2000), Mead gave us "an empirical self that is reflexively conscious of the working organization of roles that constitute it as a social structure" (p. 31).

This then leads to the theory of symbolic interaction, whose main proponent was Herbert Blumer from the University of Chicago. Holstein and Gubrium (2000) describe it as the "principle, that individuals respond to the meanings they construct as they interact with one another" (p. 32). According to this theory, individuals not only act while influenced by their culture and society, but are also agents creating culture and society (Ibid.). Blumer emphasized the *reflexive* aspects of the self, which give it adaptability, and make it difficult to fit into a structure or schema. A reflexive self "acts toward or on itself" (Blumer, 1970, p. 282). Blumer (1970) emphasized the activity of an individual, not "merely responding" to society, but rather engaged with society, endeavoring to "meet and handle" what he or she faces (p. 283).

All of this theory might seem to be distant from the topic of caregiving, but if changing identity is one of the issues causing strain for the caregiver, then it helps to incorporate a framework that empowers individuals. Symbolic interactionism, with its roots in social psychology, captures the image of an active individual, one who meets the challenge of changing identity, one who adapts to the changing social self, the looking-glass-self.

Blumer also asserted the importance of meaning, and that individuals act toward things on the basis of the meaning of the things to themselves (Holstein and Gubrium, 2000, p. 33). Individuals discover the meaning in social interaction. Certainly, social interaction is a source of great meaning, both positive and negative, for the caregiver. The caregiver can be validated through social interaction, but also can be shunned through the withdrawal of society. It is this second aspect that surfaces in Goffman's (1963) writings about stigma. According to his theory, society establishes ways of categorizing people, basing these categories on shared attributes which seem ordinary or natural. When an individual should fit that social category, but for some reason is different, in fact, "less," the individual becomes someone bad, dangerous, weak, what Goffman refers to as a tainted or discounted person. This is stigma. Applying this to the caregiver actually includes the "caregiving couple identity," because the caregiver is associated with the source of the stigma, the dementia spouse, who clearly is not a typical older person, but rather someone tainted, "less." By association, the caregiver spouse is also tainted, because the couple identity is tainted.

Stone (1970) speaks of identity as related to how a person is "situated." The individual is situated, has a position joined together with other persons or "objects," but also set apart from still other "objects." Perhaps the caregiver, situated next to someone with a dementia, and increasingly set apart from those who are well, is being forced into a new identity, one he or she hasn't sought, but one he or she must act upon, act "as a dementia spousal caregiver" (p. 399).

The caregiver identity, with its stigma, includes many new social roles related to the situation, roles totally new, and not entirely welcome. Deutsch and Krause (1965) addressed social psychology on the basis of roles. They described a culture within society as having norms or expectations. Some are prescribed, some are subjective to the individual's position, and some are enacted as the individual interacts with someone in another position within the society. Each individual has a role set, with a range of behavior expectations, but some do not conform to the expectations. This is the origin of deviancy. People with dementia no longer live up to these norms or expectations, so they are not only covered in stigma, but also viewed as deviant from what should be expected from the role as an elder in society. Furthermore, the roles of the caregiver spouse are also deviating from what spouses would typically do. Rather than walking side by side, the caregiver must often lead the dementia spouse; must be the one to make decisions; must assume all driving responsibilities, household responsibilities; and ultimately care for the dementia spouse as a parent rather than a spouse.

This changing environment for the caregiver spouse is one increasingly without communication as it previously existed for the couple. Yet communication is the path to meaning according to symbolic interactionists. Glaser and Strauss (1970) raised the concept of awareness, deemed by them as central to interaction, and thus communication. They used the term *awareness context* to express what each partner in an interaction "knows about the identity of the other and his own identity in the eyes of the other" (p. 397). Dementia couples would seem to be in a closed awareness context, i.e. the dementia spouse may not know the well spouse's identity, nor the well spouse's view of the dementia spouse's identity. In addition, the well spouse is also not clear about the day-to-day identity of the dementia spouse, nor can the well spouse always know his or her own identity in the dementia spouse's view. Furthermore, early on in the dementia, the dementia spouse learns to mask his or her losses, and put on a "performance" of competency, in the word of Goffman (1959). If Goffman were looking at the dementia couple, he probably would see the dementia spouse as wearing the mask that represents his true self, the self the dementia spouse wishes to be. Indeed, during the pre-diagnosis time of dementia, the well spouse may also see this mask as the true self, the self the well spouse wishes were his or her spouse's.

Dementia actually throws a special challenge at symbolic interaction theory, because of the shifting levels of awareness within the caregiving dyad. It is hard to have a looking-glass self if the person you are interacting with, does not remember who you are. Thus, it seems that the experience of dementia caregiving for a spouse, carries with it special identity risks. Duck and Lea (1983), wrote about endangered personal identity following a breakdown in a relationship. Although they do not address the specifics of dementia, they do see social identity as being imperiled when the relationship of a couple, fails. As part of their narrative, they include three properties which do not exist except within relationship: similarity, intimacy, and public identity (of the relationship) (p. 54). These are interesting to contemplate, using the lens of dementia. All three are seriously threatened, even though the spouses continue to co-reside. They are no longer as similar as they were; they have very limited moments of intimacy; and their public identity is stigmatized. Both spouses find their individual identities threatened, because they have, in a sense, lost part of themselves, owing to the changing nature of the relationship.

Furthermore, the well spouse is floundering owing to the loss of the self-consistency formerly developed in his or her interaction with the other spouse. These are the aspects of the self that "belong together" but now are in transition (Deutsch and Krauss, 1965, p. 181). George (2000) argued that older adults are strongly motivated to protect the sense of self, and credits them with more adaptability, allowing them to do just that. George, however, recognized that the social self is more susceptible to the threats of aging, and therefore asked for greater acceptance of a theory of an "invulnerable self" which is perhaps the same as her use of the term, "authentic self". She admitted the toll on the social self of aging, but countered this negative view with the suggestion that aging actually allows the "authentic self" to emerge. However, she also admitted that there is no empirical evidence for this concept. This, then, begs the question of whether there is room in social psychology for George's appeal.

One additional article deserves attention when discussing the identity issues of the dementia couple, and that is Stryker and Burke's (2000) work on identity theory. The theory takes James and Mead as the basis, and then extends those theories to include the multi-faceted aspects of social organization in the 21st century. The major link seems to be James' belief that we have as many social selves as we have groups within which we interact. Each group-based self gives us an identity (p. 286). In each group, individuals have a position (situation), and thus, a role to play. Social roles are those behaviors that are expected based on the position occupied. Identities are what individuals internalize about role expectations. Finally, Stryker and Burke say that we organize these various identities into a "salience hierarchy" which is determined by the individual. These identities are cognitively-based "schemas" that help us define situations, and give us cues for how to behave (p. 286). Furthermore, "commitment shapes identity salience shapes role choice behavior" (p. 286).

How does this relate to the dementia couple? First of all, commitment is at the basis of most elder married couples. Their marriages have stood the test of time, with many of them now approaching anniversaries of 50 and 60 years. Therefore, in the Stryker/Burke theory, identity salience would be very strong for their married identity, based on the commitment. The role choice of spouse is one that actually would lead them to vacate other roles and identities, if necessary, in order to practice the behaviors associated with being a spouse. Indeed, dementia caregiving requires that the well spouse abandon most other relationships in order to carry out the demands of the spousal identity. The question is whether the spouse will have the same commitment to spousal caregiving as he or she had for other aspects of the marital identity, and if not, what then?

There are a couple of related studies that used the lens of gender to look at identity. They raise the question of what happens when various identities collide in new requirements for a particular role. For example, what happens when males are called upon to show nurturing, patient, physical care for a dementia wife, and this doesn't fit the identity "constellation" so far developed in their seventy or so years up to that point? They are committed to the relationship; they derive meaning from it; yet physical caregiving isn't one of their identities. This incongruency causes stress, and perhaps some of the aggression seen in some couples. Savundranayagam, Hummert and Montgomery (2006) refer to this as a **mismatch** and found that this led to higher levels of stress for the caregiver.

Calasanti and Bowen (2006) looked at this challenge toward gender identities during caregiving, and explored the “extent to which gender may influence how spouses experience care work” (p. 253). They described a process that they called **crossing gender boundaries**. They found that gender differences showed up in how the care is provided and experienced. Their qualitative sample was small (n=22), and divided almost equally between men and women. Both male and female caregiver spouses had to cross gender boundaries in their role of caregiver spouse, in order to maintain their independence as a couple. The usual pattern in this sample was for women to have to take on more household and car maintenance, as well as become the financial organizer for the couple. Both of these tasks required decision-making confidence, which may also be a gender boundary cross-over. For the male caregivers, the obvious challenge for this cohort, born and raised before the roles for men and women changed, was the need to do cooking and cleaning. In both cases, the male and female cross-over, often precipitated reaching out for support from other family members, or friends and neighbors.

Personal care to a spouse is one of the behaviors of caregiving that asks the caregiver to perform the role in such a way as to support the care receiver’s identity and dignity. Calasanti and Bowen found that spouses worked hard to maintain the gendered identity of the physical appearance of their dementia spouses. This protection of the gender identity extended to making sure that the husbands had some money in their pockets, as well as a driver’s license. The male caregivers allowed their wives to perform household tasks like dishwashing, even though they would have to do it again.

Why so much effort to protect the gender identity? Could it be that by shoring up the gender identity of the spouse, there was still an affirmation of them as a married couple? This would also soften the stigma, and in turn, strengthen their threatened identity as spouses.

The area of identity is complicated, complex, and full of potential for better understanding what can be positive in caregiving and what can be shatteringly negative.

There aren’t many dementia studies that use symbolic interaction or the identity theory of Stryker and Burke. Again, the emphasis has been focused primarily on burden, and how to address that burden. Yet Stryker and Burke, as well as all the symbolic interactionists, suggest valuable paradigms for evaluating the identity conflicts facing the dementia couple. The flux, stigma, and confusion of the extreme role reversal that often accompanies the dementia diagnosis, as well as the changing communication patterns between the spouses, seriously challenge the adaptability of both spouses to the new “situation” they find themselves, and their resulting new identities. It isn’t hard to imagine the extent of the stress or burden both spouses may be feeling.

This review of literature pertinent to the research question concerning the origins of the high level of burden for spousal dementia caregivers when they begin assisting with an Activity of Daily Living (ADL), begins to throw light on the suggested relationship to identity stressors. Using symbolic interactionism as a structure for exploring the meaning of social identity, there appear to be many relevant theoretical underpinnings for the relationship between changing identity and increased burden. At the same time, it is clear that it is not only the caregiver spouse experiencing the stress of changing identity and roles, but also the care receiver. Their identity as a couple may become part of the story.

Furthermore, the marital relationship itself is under siege when dementia is the source of the role reversal. Reviewing the research on dementia caregiving and spousal caregiving suggests many reasons why levels of burden would be higher for spousal dementia caregivers than for other caregivers. Tying all of these factors together supports exploration of a stage theory approach to the spousal dementia caregiving experience, as shown in the work of many other researchers reviewed in this chapter. Perhaps it is the sequencing of events in the progression of dementia that pushes researchers to theorize about stages and transitions, as they attempt to bring order to what is an increasingly disordered experience for an aging couple.

The next chapter explains the method chosen in order to pursue the research question. With so much quantitative and qualitative research already in existence, it is important to state that there are still gaps in our understanding of the caregiver journey.

The method chosen for this study will explore the spousal caregiver’s negotiation of the new identity thrust on him or her by the disease.

CHAPTER II: METHODS USED IN THE STUDY OF SPOUSAL DEMENTIA CAREGIVERS

This qualitative study into the identity issues that face spousal caregivers of persons with dementia grew out of the studies conducted by Farberman, Finch, Horowitz, & Lurie (2001) and Farberman, Finch, Lurie, & Morgan (2003). These two studies showed that the period of peak burden for caregivers occurred during the middle stages of caregiving, when there was a shift from Instrumental Activities of Daily Living (IADL) support to Activities of Daily Living (ADL) support. The increased burden was greatest for spousal caregivers of those with dementia. The question is why? Although much research has been done on the general subject of burden, there appeared to be an opportunity here to delve into the identity issues of spousal caregivers, specifically to evaluate what was happening to these spouses, and thus make it easier to develop policy that would support them.

Qualitative research is especially helpful when either very little information is known about a subject or when quantitative research reveals a gap in the literature. Then the qualitative approach allows the researcher to get behind quantitative survey answers and delve into the psychological and social aspects of the caregiver's situation. Of the qualitative approaches, the grounded theory tradition of research lends itself most directly to arriving at a theoretical framework for describing the role of identity in the caregiving experience. Grounded theory (Glaser and Strauss, 1967) allows the question arising in the quantitative caregiving studies to evolve through in-depth interviews with spousal dementia caregivers, using the method of constant comparison to developmentally reframe the interview guide, look for deviant cases, and ultimately construct a theoretical framework.

The grounded theory approach will not only look at individual spousal caregiver identity, but may shed light on the stages of caregiving. There are a few theories of caregiving stages and transitions (Gaugler, Zarit, and Pearlin, 2003; Montgomery and

Kosloski, 1995; Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003). However, these theories revolve more around events than around the caregiver's changing identity. This gap in the research is an invitation to look more deeply into the complex changes that the spousal caregiver faces, and thus a grounded theory approach seems especially appropriate.

Because interview subjects will be limited to spousal caregivers, there is an implied "couple context" to the developing theory as well. Both partners, caregiver and care receiver are experiencing the progress of the disease, and their identity as a couple is also developing and changing. Thus, this study also develops an empirically grounded conceptual model of the social (joint) identity of spousal caregivers and care receivers within the context of dementia.

Time Frame for Data Collection and Analysis

The recruitment of subjects, schedule of interviews, and transcription of recordings occurred between September, 2004, and February 2007. The final transcribing and analytical work was done in Spring and Summer of 2007. Each aspect of this process is described in full below.

Study Population and Setting

The participants for this study were selected from a purposive sample of spousal caregivers. To be considered for the interview, the caregiver had to be a spousal caregiver, and the care receiver had to have a perceived cognitive deficit. There was no requirement for a definitive diagnosis of Alzheimer's disease or other dementias, although most respondents referred to diagnoses that probably came from physicians. Sources of potential interviewees included: dementia caregiver support groups, the Alzheimer's Association, adult day care programs, churches, home care agencies, Area Agency for Aging, senior housing coordinators, as well as social workers and nurses in a local professional gerontological organization.

Building on personal contacts with members in these organizations and facilities set the stage for recruiting participants to the study. Since the nature of the interview was viewed as personal and painful, these contacts and professional relationships positively facilitated the search for respondents. The investigator had already established credibility in the gerontological community, over a period of 25 years of professional engagement with that community.

Initial contact with referral sources occasionally produced an invitation to speak to a group of caregivers, or social services providers in order to solicit participants. This sampling approach made it possible to recruit 40 respondents, all of them spousal caregivers for people exhibiting symptoms of a cognitive disorder. One very productive conduit was a support group for dementia caregivers, both spousal and filial, where positive “word-of-mouth” reporting back to the group by early respondents, encouraged other caregivers to come forward. Satisfied respondents also assisted with recruiting by contacting friends in other areas of the region and urging them to participate. “Snowball sampling” allowed the universe of respondents to grow.

However, given the demographics of the region, and the traditional under-representation of minorities in support groups and adult day care facilities, the expected White profile of the respondents became evident. Then, the investigator had to seek out minority contacts to see if any minority caregivers might be approached. The proposal for the research had anticipated this problem, and although there was no mandate to represent minority caregiving experience, especially with a sample of 40 respondents, it had always been the goal to include some minority cases. Fortunately, two Black caregivers and one Asian caregiver volunteered. There was no attempt to include Latino caregivers, mainly owing to the language barrier, because the researcher did not know Spanish. The minority caregivers should not be seen as representative of minority caregivers in general, but as cases who may contribute something new or different to the emerging theory.

From a gender perspective, the numbers were more representative of the gender breakdown of older adults because of differences in longevity. Approximately one in four caregiver respondents were male, and the rest female. There were enough males (n=11) to make some comparisons with the female respondents.

Another demographic difference involved the ages of the respondents, since it may be that spousal caregiving differs by the age of the caregiver and/or the care receiver. Most of the early respondents were older, between 75 and 80 years of age, so as the interviews continued, it was necessary to seek out younger respondents, particularly those between 45 and 65. At the very end of the interviews, when the other age categories had been saturated, it was fortunate and interesting to interview a strikingly young caregiver, whose spouse had suffered a brain injury at a young age. This respondent was truly a deviant case, and challenged the emerging theory in significant ways.

Other demographic differences may also affect the emerging theory. Religious belief and practices often arose during the interview, and seemed to be very important to some of the caregivers. Again, many of the original interviewees were Roman Catholic, but other beliefs were also expressed. Still, many of the respondents indicated no particular religious affiliation. Thus, religious affiliation did not become as crucial a sampling issue as race, ethnicity, or age.

By using the snowball sampling technique, one successful interview sometimes led to referrals for other interviewees. This technique helped draw in another population of respondents, those who did not use services. Again, many of the initial respondents were already in a support group, and had tried adult day care. Snowball sampling helped the investigator find isolated cases, where there was almost no contact with support services. A second way of reaching that population was working through church groups, who knew of cases that would otherwise be hidden. This was the hardest part of the caregiver population to find, those who do not access services; yet they are crucial for discovering why caregivers do not access services.

Because only forty cases were included in this study, representation across racial, ethnic, religious, gender, or age lines was never promised nor expected. However, these demographic variables were always in mind, in order to find new cases for comparison or contrast. The intention of this study was to arrive at general principles regarding identity stages and transitions which might then be tested on larger, representative samples via quantitative methods, insuring a broader spectrum of diversity.

Table 1 provides a snapshot of the socio-demographic profiles of 40 respondents.

Table 1: Empirical Table of Respondents, N=40

Gender	
Female	29
Male	11
Age	
30-49	1
50-59	3
60-69	11
70-79	18
80-89	7
Race	
White	37
African American	2
Asian	1
Religion	
Catholic	15
Protestant	5
Jew	4
Undeclared	16
County	
County A	6
County B	34

Initially, the design sought to include only those in the middle stages of dementia caregiving, but that proved too limiting. During recruitment, caregivers at all stages of the experience responded. This was the first major change in the planned selection of respondents. Finding any spousal dementia caregivers willing to share their stories was a big enough challenge; trying to limit them to cases in the middle stages of caregiving was not only too limiting, but also very hard to measure. As it was, many caregivers volunteered who were not spouses and had to be gently rejected. By including those who were further along in their spouse's progression of the disease, it actually was easier to see what was different between the middle stages and the end stages. The final results would not have been possible without the full range of caregiving experience.

Researchers who recruit older adults always risk illness or loss in their respondents. This turned out to be the case for three of my respondents. In two of the cases, the caregivers consented to doing the interview while their spouses were still living at home. But by the time of the actual interview, one of the care receivers had died, and in the other case, the care receiver was hospitalized, just before the interview began. Because the caregiver was somewhat distraught over this change, that interview was terminated early. The next contact with that respondent was after her husband's death. The interview resumed when the respondent felt comfortable enough to begin again. The third caregiver who did not specifically fit the guidelines of providing care to a dementia spouse at home, was still chosen for her unique perspective. The researcher had met her in the support group, because she still attended despite the fact that her spouse had died within the previous months. She had a long caregiving interval and had undergone the full caregiving experience from home, to nursing home, back to home for hospice. Her memories were fresh enough to make her a good candidate, and she added a perspective no other caregiver could have.

There were also three different cases where the spouse had already entered a nursing home at the time of the interview. Again, it appeared that their commentary might add another important lens for the theory that had been developing in the early interviews. Their stories helped fill out the spousal caregiver experience, and complemented the data already collected. During the analysis of the data, it became clear that the resulting theory could not have been possible without these interviews. What originally seemed like a major divergence from the goal of the research, actually ended up expanding on the conceptual framework, by allowing the investigator to see its applicability to the later stages of caregiving.

Regarding the setting for the interviews, the goal was to meet the caregiver in the home setting, thus picking up the context of the experience. From the beginning, the decision about whether to have the interview when the care receiver was present, was challenging to caregivers. Most preferred to have the interview without the care receiver's presence, but some could not avert that situation. There were positive and negative aspects of a care receiver's presence. The caregiver was less relaxed. He or she often had to tend to the care receiver. The care receiver was curious about the stranger. Some were threatened by the stranger's presence. Most of the care receivers would interrupt at some point in the interview, but most were content to have lunch or watch television. In 17 of the interviews, the care receiver was present for part of the interview. Two of the 17 care receivers were uncomfortable with the presence of the interviewer. In one case, the care receiver visually threatened the interviewer, by removing his belt and shaking it at her. In the other case, the care receiver was highly agitated, and constantly interrupted the flow of the interview.

With the exception of the above two cases, the presence of the care receiver was usually easy to accommodate. The interviewer addressed the care receiver, if he or she seemed receptive, and, in a friendly manner, engaged them in the interview proceedings while he or she was present in the room. However, their presence was usually of a very short duration, and they returned to television in another room. For the most part, the presence of the care receiver was not overly distracting to the caregiver, with the exception of the two cases mentioned above.

In the remaining 23 cases, the caregiver preferred to have the interview while the care receiver was at adult day care, or had been taken out by an adult child. They purposely set up the time of the interview for when they would be alone. Although this let the interview proceed better, without interruptions, it did detract from the context. The interviewer never really saw the person who was the subject of part of the interview. If there were problem behaviors, they were not witnessed.

Aside from the care receiver's presence, the other important aspect of the setting was the room in which the interview was conducted. Usually, the caregiver let the interviewer decide where to conduct the interview, and usually the interviewer chose the kitchen table. The digital recorder did not require any plug, but it did require a general background quiet. When there was background noise, as from a television, radio, or in one case where workmen were present in the house, the quality of the recording was in jeopardy. Sometimes, the interview had to be moved to another location because of this background noise.

The goal of the interviewer was to make the caregiver as comfortable as possible. If he or she offered tea or coffee, the interviewer often took them up on the offer, or asked for water. Sometimes the interviewer brought breakfast coffee cake to the interview, in the hopes of creating a friendly, comfortable environment. The cake was also a traditional way of saying thank you for allowing a stranger into your home. Sometimes, there would be an early discussion before the recording began, about the house, the property, the pictures of grandchildren, etc. All of this helped both interviewer and respondent to become more comfortable with each other.

In most cases, the home environment was very orderly, considering the full time presence of a spouse with dementia. In only two cases was the home less orderly. The first case involved an 82-year-old male caregiver in a small apartment, and the second case involved a 73-year-old female caregiver in a small cottage. That caregiver admitted suffering from depression, and had in fact refused the interview at first, because, in her view, her home wasn’t fit for a guest. When she obtained the service of a cleaning woman, she then agreed to the interview.

In fact, all of the other home settings for the interviews were cleaner and more orderly than most people’s homes. It was almost as if by keeping an orderly home, the caregiver was taking control where he or she could. Some of them admitted spending a lot of time cleaning every day. At any rate, the home environments were generally a testament to the caregivers’ mastery of their environments.

In only two cases was the interview held in a location outside the home. One of those was held in a nursing home where the dementia spouse is now a resident. Practically every day, the caregiver spouse uses public transportation to visit her husband, and so the interview was conducted at that location, actually giving more insights than the home would have given. We sat in a quiet common area, and the husband was wheeled out to be with us for part of that time. This setting showed me what the caregiver faced every day in order to maintain her relationship with her husband. However, she spoke very quietly because she didn’t want people to overhear her comments, particularly about the nursing home. This made it difficult to understand during transcription. So it was both a positive and negative choice for the interview.

In the second case, the caregiver was unwilling to bring anyone into her home, because she felt her husband would react negatively. She also was worried about leaving her husband home alone too long during the interview, which was held in the same location as the support group meeting. Her husband did not attend with her, and she didn't want to keep him waiting at home. Her concerns were not so much what her spouse might do at home, but that he would be upset, possibly angry. That made the interview itself more stressful for both respondent and interviewer. Time was a pressure.

Generally, the interview would last 1-2 hours. The longer interviews occurred where the caregiver felt very comfortable sharing his or her thoughts, and actually sometimes expressed a wish for more opportunity to do that. What had motivated them in the beginning was the desire to share their story so that perhaps it might help in the research on dementia. At the end of the interview, many of them thanked the interviewer, because they felt they had received a benefit as well. Some indicated a real need for a listener.

Research Design

The initial contact with the caregiver was usually by phone. The caregiver either submitted his/her first name and phone number, or called the interviewer. The interviwer never asked for last names, but in order to fill out the informed consent (Appendix I), the last name was recorded, but not used by the interviewer. All appropriate privacy guidelines as established by the Committees on Research Involving Human Subjects (CORIHS) at Stony Brook University were practiced. Furthermore, specific diagnoses and prescribed medications were never formally sought and recorded. However, in the course of the interview, the caregiver often shared this information. Neither diagnosis nor medications were necessary in the analysis of the caregiving experience. What was necessary, was that the relationship between the caregiver and care receiver was spousal, and that the care receiver had a perceived cognitive deficit.

Since most caregivers wanted to guarantee the privacy of their situation and their spouse's condition, the researcher always assured them that the subjects of interest were they, themselves, and not their spouses. They were understandably put off by the length of the consent form. Many of them, especially those over 80, had little formal education, and the length and wording of the document confused them, and sometimes frightened them. On the other hand, some were very interested in the legal tone of the document, and had specific questions to ask regarding certain lines in the document.

The subject of the consent form is actually related to issues in qualitative research methods. Qualitative research requires that the researcher usually be unobtrusive, and non-threatening. In order to help the respondent feel comfortable enough to share personal beliefs, attitudes, motivations, fears, joys etc., the researcher works very hard to set up an extremely comfortable interview setting. As was stated above, time is spent engaging the respondent ahead of time, so that he or she is more willing to fully participate in the interview. But before the interview can start, the respondent is asked to read and sign a consent form, which is full of legal-sounding jargon specific to the research community, and intended to protect the rights of the respondent. The intent of the document is good, but the form is threatening, particularly to older respondents. All of the good intentions of the researcher seem to rest on shaky ground, when the document is brought out. Many of the older respondents were confused by it. At that point it takes all the social interviewing skills the researcher possesses to manage the comfort levels for the respondents and keep them engaged in the endeavor.

Understandably the consent form is meant as a protection against some of the harmful research practices of the past, but for some populations, it can be problematic. Qualitative researchers need to be aware of this beforehand, and go into the setting prepared to balance the legalistic tone with their own social skills.

Similarly, the recording device itself has been shown to make some respondents ill at ease. However, the small digital recorders available today reduce some of that anxiety. There is no microphone that must be spoken into; no tape to run out. However, the researcher must come prepared with spare batteries, and watch for signs that the batteries are fading. The failure of the batteries occurred once during this study, and required that a second session be scheduled. Although, the researcher tried to recapture the essence of what had been lost in the first attempt, there were limits to what could be done in a second attempt.

The interviews were recorded digitally using an Olympus digital recorder, and were then downloaded to a computer, from which they were ultimately transcribed verbatim. The sound quality of the interviews was generally quite good, but this is another area where practice ahead of time helps make sure the session will be successful.

An interview guide was created for the interviews and is shown in Appendix II. All interviews began with the open-ended request, asking the caregiver to tell his/her story. This immediately put the interview under their control, and greatly alleviated any discomfort that they may have felt. Additional probing questions were used to include how the couple met, how long they were married, etc. This introduction gave the respondent a chance to provide the context for their spousal caregiving relationship and was very helpful later in the analysis for building a couple identity. As the interview continued, there were additional questions related to the topics of changing roles and responsibilities, and changing perceptions of the caregiver's own identity.

- When did you first know that you were a caregiver?
- Can you describe feelings you might have had at that point?
- How has your relationship with the care receiver changed since you became his/her caregiver?
- Do you look at him/her in a different way?
- Do you see yourself differently?

These intensely personal questions were followed by questions about perceived need, use of services, sources of social support, and communication with others. For example, the caregiver was asked if there was something he/she did, which he/she would really like someone else to do. Questions like this gave the caregiver an opportunity to share where the problems were. If the caregiver never mentioned adult day care, or support groups, the interviewer would ask specifically about those services, in order to get a base line of what services the caregiver actually used.

There were many additional questions and probes, but each interview had a life of its own, with new questions emerging. This is the typical technique of grounded theory interviews, allowing the interviewer the flexibility to explore each respondent's individual experience. The length of the exchange varied from one hour to two hours. The average was one and a half hours.

Additional information recorded in an interview journal about caregivers included the first name of the caregiver, location of the housing, ages of the caregiver and care receiver, brief descriptive notes about the caregiver, and general comments about the experience of the interview. After leaving the interview, the researcher would often sit in the car and note some of this information, or would type it up when at home. In most cases, additional demographic information was sought, such as ethnicity, religion, years spent caregiving. Since this information was imbedded in the interview, tables have been created to present this information.

Once the researcher returned home, the digital data from the recorder was downloaded to a computer, which had software installed for the recording device, so that the interview could be heard through the computer. Then, the researcher saved the recording not only to the hard disc of the computer but also to a computer disc (CD) so that a back up copy would exist. These recordings on CD can only be heard through computers which include the Olympus software.

For the first twelve interviews, the investigator transcribed the material herself, using a foot pedal adapted to the computer, allowing her the ease of going back and forth in the recording in order to pick up missed information. Although a good typist, the investigator learned with those first ten interviews that transcribing is an art, and ultimately found a transcriptionist who was willing to learn to use the Olympus software and pedal on her own computer. However, in the process of coming to that decision, the researcher lost a lot of time.

With the introduction of an outside transcriptionist, a significant cost factor in this kind of research, the analytical process was able to progress. Rather than focusing on transcribing, the investigator now could enter the Microsoft Word transcriptions into the analytical qualitative software chosen for this project. Choice of software can become another stumbling block for the beginning qualitative researcher. Traditionalists who follow in Anselm Strauss's footsteps shy away from both recorders and software, trying to stay as close as possible to the words of the respondent. However, with ultimately approximately 80 hours of interviews to analyze, the investigator chose to explore technology options that might help organize and manage the data. There are numerous choices today for this kind of software, and again, there is a financial investment. It was the good fortune of this interviewer to discover that one of the major training sources for qualitative software, ResearchTalk, Inc., was located nearby. By enrolling in both the beginning and intermediate levels of training for one of the programs, ATLAS.ti, the data could be rolled smoothly into the ATLAS.ti format. Although not simple to use, hence the training, ATLAS.ti is user-friendly, and performed very well as a management tool for the data.

For the analysis, all names were changed to protect the privacy of the respondents. The initial theme for the coding of the interview data was the theme of stress. Quickly it became clear that there were two people with stress in the stories: the caregiver, and the care receiver. From this first dichotomous code, many others also split into two: Health, Mastery or Lack of Mastery, Anger, Identity, and Activities. ATLAS.ti also allows the formulation of diagrams which helped conceptualize what was happening to the caregiver. During the first ten interviews, using the process of open coding, and some axial coding, 56 codes were chosen to categorize the experience of the caregiver. Additional codes were added during the continuing analytical process of axial coding, showing the relationships that seemed to exist between codes. Furthermore, the category of medical interaction grew to become a significant, although unexpected, source of stress for caregivers, thus leading to more axial coding. By the end of the analysis, there were 78 codes, 19 of which related to the theory developing around the unexpected finding of medical interaction as a source of stress for caregivers. (See Appendix III for the total list of codes.)

Besides coding and creating analytical diagrams, the software allows for the creation of memos, which again, helped with the process of developing a conceptual framework. In fact, early memos written to describe a specific interview or respondent, actually contributed to the development of the grounded theory for this study. Again, the software allows one to manage all this data in one location, as in a file cabinet, and yet have much quicker access to the material when needed. The software does not think for the investigator, nor theorize for the investigator, but it does allow the investigator to manage the data efficiently, and retrieve it flawlessly. It becomes the pen, paper, and notecards of the project. When one looks at the code for “Caregivers and Driving Issues,” ATLAS.ti is able to immediately tell the researcher there were 96 times in the 40 interviews, where the code had been used, and then allow for access to the specific quotations in each specific interview, so that the investigator can revisit the context for that coding decision. Finally, the investigator can simultaneously read any note made about the quotation at the time it was coded. This is what is meant by “managing” the data.

ATLAS.ti also allows the researcher to create a spread sheet of all the codes and their numerical frequency per respondent. Thus, it was possible to suggest relationships between codes. For example, was there a relationship between the number of times caregiver stress was coded in an interview, with the number of times medical interactions were coded in an interview? Because the coding is subjective, it is only possible to speculate about relationships, but these relationships can be more easily disclosed using the software. Along with axial coding, and the development of network views, the interpretive analysis progressed. (Appendix IV shows a sample network view, as well as an explanation of the network.)

It should be kept in mind that this study is qualitative and grew out of questions from earlier quantitative literature, and a perceived limit in the discourse about stages of spousal caregiving. Using grounded theory methodology, the analysis shows that there may indeed be stages in the spousal caregiving relationship, and that individual caregiver identity may not be as significant to what is happening as the couple’s joint identity. This method allowed the researcher to apply the theory to all forty couples, and find only one case that did not conform to the conceptual model, for clear and significant reasons.

If there are any weaknesses to the use of this research approach in this study, it would be that owing to limitations of personnel and funding, the investigator was not able to triangulate methods or sources in a way that might add rigor to the study. Of chief concern, would be the use of an additional analyst/observer, who could have checked for inter-subjective agreement. By coding the same interview twice, it would have been been a good check on the researcher's coding consistency. In a larger study, with financial support, this surely would add to the strength of the findings. There was only one investigator for this study.

This study, in total or in parts, also could lend itself to alternative research methods. Some of the findings strongly suggest that as a next step, the question about medical interactions being a source of stress for caregivers, particularly female, younger caregivers, should be explored. A quantitative survey certainly would allow physicians and advocates an opportunity to decide if this issue has become significant enough to address.

Having presented both the strengths and weaknesses of the research methods incorporated into this study, the next chapter will begin the exploration of the findings. The conceptual framework established during the analytical part of the research project, is large enough to warrant dividing the findings into three chapters, each one representing a different part of the couple's journey into dementia and caregiving. There is one additional chapter addressing the unexpected finding concerning the role of medical interactions as it relates to caregiver stress.

CHAPTER III: RESULTS SHOWING STAGES 1-3 OF SYMBIOTIC STAGE THEORY

Introduction: The Metaphor of Symbiosis

The goal of this research was to interview spousal caregivers in the middle stages of caregiving to try to expand on why that was the period of peak burden as shown in earlier research. Most of the 40 spouses interviewed for this research were actually in the middle stages, but many were past that point on the caregiving trajectory. Because it wasn't always possible to ascertain where the caregiver was in the process until each one was interviewed, and because it wasn't easy to recruit subjects in a timely manner, the range of caregiver experience was significantly broader than originally expected. This opened up the possibility of looking at caregiver identity, a social concept based on social interactions, from different time perspectives, and added some breadth to the information gathered.

Originally, shifting "identity" was viewed as a possible reason for why spousal caregivers midway into the caregiving experience were expressing such great burden. Thus, the interview guide included many questions about identity and the analytical codes included several related to caregiver and care receiver identity. The results did show a distinct change in the caregivers' perceptions of their own identities, as well as their perceptions of their care receivers' identities. This change often occurred simultaneous with a specific event that dramatized the care receivers' lack of mastery with resulting increased dependency. In other words, the caregiver began to assume a new role in the relationship, a role that was never expected, and with it the imperative to negotiate a change in identity. Most could say **when** they knew they were a caregiver.

Individual identity is a major factor in the findings, but so is the conceptualization of the couple's identity, as a symbiotic pair, borrowing the direct meaning of symbiosis from biology. Symbiosis is the coming together of two different organisms, to interact, for their mutual benefit. The word itself is from the Greek, *symbioun,* "to live together." There are usually three types of symbiotic relationship in biology: mutualism, commensalism, and parasitism. In mutualistic symbiosis, both organisms benefit from the interdependence. In commensalistic symbiosis, one is indeed weaker and benefiting more from the relationship, but is not doing any harm to the other organism or host. Finally, there is parasitic symbiosis, where one organism is living off of the other organism, and weakening that host organism in the process.

This biological concept seems readily adaptable as a metaphor to many other relationships in the natural world, and in the technological world. Thus, it is not surprising that the concept of symbiosis is fairly common in our culture, and has been applied in many fields. Starting with biology, the biologist Lynn Margulis researched bacteria and the role of symbiosis in the evolution of cells (Brockman, 1995). Her research has led her to emphasize the role of cooperation in evolution, the cooperation based on the symbiotic process. She still accepts the Darwinian theory of competition as an explanation for evolution, but feels it is incomplete, without including the role of symbiosis, a *cooperative* aspect of evolution. In the field of modern day ecology, as demonstrated in Boucher's (1985) text, there is a similar emphasis on the concept of mutualism in evolution, also borrowed from the theory of symbiosis.

Furthermore, the field of information technology has also appropriated the metaphor, symbiosis, to describe the relationship between human beings and artificial intelligence. Norman Johnson (1998) of the Symbiotic Intelligence Project at Los Alamos Laboratory, describes the goal of the Project; that is, to analyze and facilitate how people and smart networks interact, based on principles of social evolution.

Perhaps the closest relationship to this research is the use of the term in psychology. T. Horner (1992) surveyed the beginning use of the term, symbiosis, in biology in 1879, when it was used to focus on a physical relationship between two organisms. In the 1940's, Eric Fromm used symbiosis to describe the "infantile dependency ties of neurotic adulthood" (Horner, p. 28). The negative connotation of symbiosis for Fromm changed as other psychologists such as Therese Benedek and Margaret Mahler saw symbiosis as a stage of development for the two-to-three month old infant. However, Mahler also labeled the problem of the child who cannot differentiate from the mother, as a symbiotic problem in the field of object relations. Horner (1992) describes the use of the term symbiosis in psychology as a metaphor and sees it as a "wish," the desire to establish a state of oneness, and also as "withness," a lasting relationship implying reciprocation (p. 33).

Lewis (1973) extended the metaphor to include relationships between adults, but related his research to previous work on mother-infant relationships. Davis (1984) used symbiosis to describe the relationship she had with her disabled daughter, whom she could "empathically understand" during the daughter's early adolescence (p. 2). She sees the imbalance in dependency, thus less mutualism, but wants to emphasize the reciprocity aspect of the relationship, rather than the dependency.

One of the more recent adaptations of the symbiosis metaphor is the psychotherapeutic theory of Transactional Analysis. During the 1960's Eric Berne published his popular text, *Games People Play***.** White (1997) refers to symbiosis in transactional analysis as when two individuals act as though between them is a complete personality (p. 300). The article is interesting in that White brings out the notion of attachment hunger, and says a symbiotic relationship in adulthood allows that hunger to be sated. "As this hunger is so primal to humans we can see why symbioses are at times so hard to end" (p. 303). This brings us back to the subject of the current research, spousal caregivers and dementia care receivers.

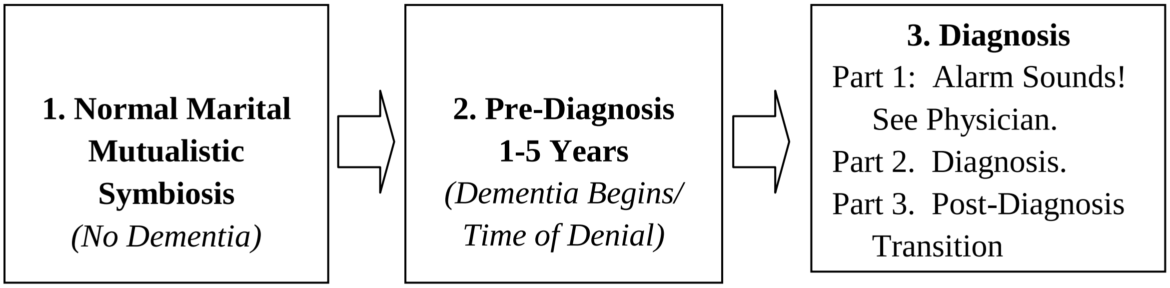
In the interviews, the term almost immediately surfaced in the investigator's notes for Amy (I-1), the 75-year-old caregiver who was finally able to leave her afflicted spouse with an adult child for a weekend, and visit close friends in Pennsylvania. However, not only does she worry about her spouse the entire time she is gone, but he, meanwhile, continually asks for her, and even tries to walk home to her. She admits that the visit was not worth it, due to her worries about her spouse while gone. Immediately, the concept of symbiosis goes into a memo: "**Their focus on each other, when apart, made me think of symbiosis.** I will look up symbiosis, and see how it might fit the caregiver dyad. This may be a relevant concept when looking at Alzheimer spousal relationships."

Indeed, at the end of the analysis of the interviews, that one metaphor, the symbiotic relationship, seemed the most vivid and exact way of describing what happens to the relationship of the dementia couple, to their social identity as a couple, and also contributes to the changing social identity of the two individuals caught up in the symbiotic relationship. As with the other metaphorical uses of the concept in ecology, technology, and psychology, symbiosis as shown in its three biological types, i.e. mutualism, commensalism, and parasitism, this study suggested that these types actually show up as stages that dementia couples experience. It is the movement from mutualistic symbiosis, to commensal symbiosis, and ultimately to toxic dependent symbiosis (parasitical symbiosis) that creates the stress in each member of the couple, and threatens their identity, both as a social couple, and as individuals, ultimately changing those identities.

Unlike biological symbiosis, which has three typologies of symbiosis, this usage of the concept uses those typologies as a process, moving along a line of development, from mutualism to dependency and in some cases, to toxicity. There are mileposts along the way, but there is no turning back. Chapters 3, 4, and 5 of this study show the stages of this process, highlight mileposts with concrete examples from the interviews, and ultimately show that the story does not always end in the same way. Although all of the stories end in dependency and some level of burden and loss, some situations are toxic and destructive to the caregiver, while others enable the caregiver to survive relatively intact owing to specific, documented mediators.

Out of forty interviews, only one did not end in symbiotic dependency. In that case, the caregiver, Kathleen (I-40), was quite young and the mother of a three-year-old. She would not allow her brain-damaged spouse to rely on a symbiotic relationship with her for his survival. She began to be the caregiver in the first six months of his injury and rehabilitation, but without external financial support, supportive caregiver public policies, personal support from his family, and the experience of a long marital history, she had to back out, in favor of the survival of the mother-child dyad. That symbiotic relationship with her child was much stronger, as a result of cultural supports in its favor. The couple relationship would end in a divorce, both legal and emotional. "…I don't know how people stay married, especially at such a young age. I always said if I was 65, 75, but I was 30 and I had a husband with a brain injury and a brand new baby and all the stuff that went along with that." She is the only caregiver out of forty cases to refuse the symbiotic relationship.

To assist in visualizing the stages described in this narrative, a complete representation of the model for the symbiotic spousal dementia caregiving relationship is shown in Appendix V. In Appendix VI is a complete list of the 40 respondents including pertinent demographic and descriptive data. Shown below is a representation of the three stages uncovered between the established mutualistic relationship of a typically married couple, into the time of dementia diagnosis, and the transition in roles following the diagnosis. These stages are the subject of Chapter 3.


Spousal Dementia Caregiving Symbiosis Stages 1-3

Stage 1: Normal Marital Mutualistic Symbiosis

The first stage in this model, is one that fits many marital relationships, a mutually beneficial interdependence. In the forty interviews, all of the couples had been married, with an average length of time being 44 years. The longest married was Kitty (I-27), 64 years. The shortest length of time was Maggie (I-11) who had only been married three years, but had been dating her second husband, eight years prior to the wedding. Nine of the forty couples were in a second marriage for at least one of the partners.

The interview usually included questions about how the couple met, and their early years as a couple, helping to clarify the prior identity of both the caregiver and the care receiver. According to Elizabeth (I-7), married 58 years, her spouse was “very charming, and still is to this very day, and very romantic, and it didn’t take a lot to fall in love with him.”

Judy (I-9) describes her decision to marry in this way:

> At the end of his junior year (college), he got a telegram from Mr. Truman, and uh, in August he was to report on September 11 for going back into the Marines, because he was a radio man. So I immediately took over, and called Monsignor Walsh. My sister and I. ‘I’m getting married on Labor Day.’ (She chuckles.) So we got married, and I went to Camp LeJeune with him, and I said, ‘As long as he is in this country, I am going to be right there.’ My Irish mother had 15 fits, but we did it, and it worked.

Lawrence (I-14), an 85-yr-old African American caregiver, describes his married life in these words: “…we communicated very easily, we’ve known each other for so long. . . We had the same political likes and dislikes. We did. Our lives were together. It was like we were raised together.”

This is how Louisa (I-29) describes her early romance: “Love at first sight, you just know. I couldn’t turn on the television without seeing Randy’s face. I was 18. . . It didn’t go over too well with my father because Randy was 33. They didn’t appreciate that but they eventually came around.”

These vignettes are a sampling of the many love stories that were shared during the interviews. The majority of the couples had 40+ years of happy marriages. They were often each other’s best friend, as well as lover and partner. They shared long years of history, war time experiences, city neighborhoods, job changes, relocations to the suburbs of Long Island, large and small families, caregiving for elder family members as well as parenting young children. Those children grew into problematic teenagers, and then went on to marry and gave their parents grandchildren. Somewhere in the later years, dementia crept into the fabric of the marriage, and everything changed.

Of course, not every couple had a happy marriage. Five of the caregivers were in unhappy marriages, but had still gotten drawn into a symbiotic experience, despite the unhappiness, with the exception of the young Kathleen (I-40). An unusual example of this "bitter" symbiosis is Laura, who constantly wavers between hating her husband, and defending his basic "goodness." Another unhappily married caregiver, Moira (I-6), was in her 44th year of marriage to a man she didn't love. This is how she describes her awakening to the realization that she was losing him.

> I guess when I saw him, and the condition he was in, the realization coming home one night, was that I might lose him. I said, that is kind of strange, after 43, 44 years. You know, to say, this is it. I never realized that before I think. You know, when the other women in the group lost their husbands, or something happened, and you would say, 'You will be ok now, the burden has been lifted, and blah, blah, blah.' But it is not that easy. And I said, no matter what the marriage had been, or the relationship has been, this is somebody you have spent half your life with, you know, and whether they were a fixture, or just, you know, somebody who sat in the chair, that was it. That's where you have been.

Thus, the marriage itself is the state of symbiosis, for better or worse. Clearly, it can be an unbalanced, unequal relationship for some people, but for the majority of these couples, the mutualistic pattern was predominant. Whether positive or "bitter," they generally supported each other to the best of their ability, and mutually benefited from the relationship, at varying levels.

Stage 2: Pre-Diagnosis

For most caregivers interviewed, there was a reference to a time before the diagnosis of dementia when they saw signs of decline but usually didn't worry about it. This is a time of denial and concern, where the normal patterns are changing, but both spouses shake off the unease, and go about their usual roles. Judy (I-9) speaks of her husband: "It was strange, it was little things. He would go to put the dishes away, and he wouldn't remember exactly where the dishes went. . . He would say, 'You moved stuff again.' Yeah, he was, 'you keep changing the cabinets.' And I would say, 'Uhuh?!'"

For Brenda (I-8), Ralph's caregiver, there were early signs: "And I believe it started before he left work, which was 62 (age) because my husband was an electrician, but he didn't just wire your house. I mean he worked in the City and he wired roomfuls of, you know, there was a whole wall just full of wires that he would do. And he would come home and start to look in books, which he hadn't done before. I didn't realize then that maybe something was happening, but he was doubting himself already."

Very often the early signs are silent, and easy for the caregiver to overlook. In most of the couples, these years are a time of change anyway, because of retirement. The care receiving spouse retires either because he/she is at the retirement stage, or perhaps because the job is just too demanding. For Kay (I-19), her husband retired from teaching at 57. "I think they introduced computers into the classroom and he couldn't do it. He could not do it."

Similarly Christine's (I-28) husband, while he was still working and in his early 60's, started to develop problems that the family did notice. "In 1991 on his birthday the kids, we all gave him a VCR. He looked, he had absolutely no idea what he was looking at … and he knew things. We thought he was kidding at first. Then I started to notice he was forgetting people's names … forgetting certain things that would be brought up."

Wayne (I-35), a 76-year-old caregiver for his spouse of 52 years, took an early retirement at the age of 62, and moved to Maine.

> I took an early Social Security and bought a house on the water … gorgeous spot." He remodeled his dream house, and settled in with his wife, a retired English teacher. Then he got an idea for a retirement business. "I started a small business, manufacturing this device which was used to help load your canoe on top of your car … for one person. . . . I developed this packaging procedure. We would work on a work bench and Jean was responsible for wrapping these two components in newspaper. . . She couldn't master that. She'd get it for about 6-8 times. I'd get angry with her. We'd have an argument and she'd go storming in the house and I'd have to finish it by myself.

It is possible to see that if these changes are accompanying retirement and relocation, they might be easy to ignore, and indeed most couples did. However, some of the couples experienced an early, much more dramatic dementia, and the changes occurred during the prime of their working years. In these cases, there were many years of financial ineptitude, medical mystery, personality changes, and angry fights, before an eventual, inevitable diagnosis. The early onset cases are the most poignant stories because they almost completely destroy both care receiver and caregiver, and there is little support from the outside until the diagnosis. The trajectory toward dependent symbiosis is a much rockier road, with toxicity occurring much sooner. However, these make up a smaller subset of the interviews, and will be addressed separately.

For the typical care receiver, these initial cognitive changes may have precipitated the retirement decision, but never seem to lead to any medical intervention. Most of the caregivers indicated a one-to-five year period where there probably were changes before they took the changes seriously. Then it is usually the well spouse who initiates the medical check-up. Sometimes, the adult children are pushing both parents to see a doctor. But for that to happen, usually the alarm has to sound, which is the next stage. Before the alarm, the changes are viewed as normal aging changes, or are not taken seriously by the caregiver. The relationship is still perceived to be mutually symbiotic but in fact, the transition has begun.

Stage 3: Diagnosis

Stage 3 / Part 1: Alarm Sounds! See physician.

This stage clearly occurs in every interview, and is a milepost in the dementia trajectory, as well as in the progression of the symbiosis. Something happens--a close call behind the wheel, becoming lost while out walking, serving partially frozen turkey at Thanksgiving--and it causes alarm or concern in both spouses, and often in their families. There is an event which suggests changing roles within the marriage, thus forcing the well spouse to look at the partnership in a new light. Dependency is setting in. Drawing from three cases, Robert, Elizabeth, and Millie, these are examples of the variety of events which cause the alarm.

I-4 Robert and the Frozen Turkey: This 65-year-old caregiver is experiencing the dementia of his spouse, a recently retired high school science teacher. Although she has always been quiet, their's seems a solid, compatible union, marked by a shared love of sailing. However, in the past three years, there have been changes: "Yes, we were on the bike riding. . . And she turned left. 'You were supposed to turn right!' 'I just did.' Oh boy. So when we got back to the house, I just did a couple simple questions. I said, 'Which is your left hand?' And she put up her right hand. I knew there was something wrong. And then it followed from that. We had different tests done." This happened about three years before the interview. At the family Thanksgiving celebration, also three years earlier, there were errors in having the turkey ready for the dinner, and in the table setting. Still, the adult children didn't mention anything.

During that same holiday period, Robert questioned his daughter-in-law and her physician father, because they had experience with a family member having Alzheimer's, and the physician replied that "he thought he saw a little something," now that Robert was mentioning it. Robert says his wife has always been on the quiet side, but he asked some of her friends if they were noticing anything different about her, and one responded, "I think the last few years I saw her being more quiet." Their family doctor recommended a psychologist, who gave her a number of tests, and then suggested the Alzheimer's Clinic at a regional hospital. There were MRIs taken, and another opinion from a second Alzheimer's Center which confirmed the diagnosis.

Two years later she spends most of her time with her spouse, crying, and he is at a very high stress level, not knowing what to do to "control" what has happened to him and to his wife. This is especially difficult for him to accept, because he is a builder, a man with a perfectly manicured lawn, and a beautiful home he built himself. Now, his identity is trapped, as he is trapped, in a relationship that increasingly was becoming dependent.

I-7 Elizabeth and the Problem Checkbook: This caregiver is 79, and her spouse, Ben, is eight years older. What marks this interview is Elizabeth's sense of respect for Ben's mind, and her anger and stress over that being gone. She has him on such a pedestal, that these losses on his part are doubly cutting to her. Their relationship was defined by his superiority (in her mind) and now she doesn't know how to define it. The changes began four years earlier, but the event that caused the alarm in their case, occurred just three years ago. She was still working, and she wanted him to be responsible for balancing the checkbook.

> He started to do it. He didn't say no. He started to do it. And after doing it about, I would say, six months, he said to me one day. "I have a problem. I am going to need your help." I said, "What is it?" He said, "It is with the checkbook." So I came in, and I said, "What's the problem?" He had not been balancing the checkbook. He just took what they said, and he was overdrawn. And we had to stop that account, open a new account. It took me months to find out where the mistake was. But we stopped using that checkbook. With the bank, I went to the bank, and they said they can't unravel it. He couldn't do that anymore. And that is really when I started major medical testing.

Note that in this last sentence of the quote, "I" started the medical testing, not "we." This use of "I" would seem to contradict the symbiosis process, but in fact it points out that his role in the partnership has receded, and she perceives her identity to now be the decision maker, his former identity.

The diagnosis does not come quickly, but ultimately, after testing for dementia at a Veteran's Hospital, Ben is diagnosed. What makes this change in their relationship interesting is that Elizabeth always felt she was Ben's inferior, at least in intelligence. But dementia robs intelligence, so Elizabeth's sense of her marriage is definitely shaken. She always knew she was more practical than he was, but that was ok, because he was the intelligent one. Since that is now gone, how does she define who they are as a couple and how does she define herself?   She is not at as high a stress level as Robert (I-4), but she is shaken, as the change in roles alters how she perceives herself, her spouse, and their identity to the outside world.

I-13 Millie and the Truck For Sale: This 78-year-old African American caregiver lives in a close-knit community, where their well-tended, middle class home is a testament to their children and grandchildren, but especially to a son, a Viet Nam-era hero, whose loss is still keenly felt by this caregiver. Millie credits two events to her discovery of her spouse's illness: "I didn't realize what was going on until I went to Virginia and my brother-in-law visited him and he said that George isn't walking right. I said what you mean? He said ok we'll walk behind him and talk. We did that and I looked … he was placing his feet like he wasn't sure. I said when I get back (home), I'll check it out."

At about the same time, she discovered his awareness of his changing capacities, particularly his ability to drive.

> I know he had stopped driving on his own. He had a little job . . . cleaning up and he asked me one morning, he went out to the truck and he came back and said, "Come on you got to take me to work." I said, "What?" He said, "You got to take me to work." I said, "Ok, no problem." I thought there was something wrong with the truck. So, I took him and the first day I sat in the truck and waited until he finished and came home and the next day, the same thing. "Take me to work." I said ok and I said I might as well go there today and do something instead of sitting there waiting. . . so we come home and then he said to me that he didn't feel right. So I took him to our primary doctor and she got the ball rolling on with what was happening.

As will be seen in this symbiotic progression, giving up driving is a key milepost in the stages. Some, like Millie's spouse, do so willingly, perhaps because of some traumatic event behind the wheel, but many, especially the males, fight this milepost. The significance of driving, to the husband's identity, is so great that, caregivers like Millie immediately notice that something must be wrong. Why would he give up driving?

> . . .one thing led to another and (it) end (sic) up he had the Alzheimer's … because I wondered why he stopped driving. I said I wonder did he go the wrong way and somebody said something to him. . . . Or he got lost and somebody put him on the right path. I'll never know what happened. But … just like that somebody tell you they are not going to drive no more you wonder why. I'll never know what happened. He put a sign on the truck "For Sale". . .

Most of the caregivers report that the early changes relate to memory issues, unless the dementia is not of the Alzheimer's type, in which case the early changes are related to poor cognitive judgment, personality changes, etc. In almost every case there is some alarm which sounds and sends the couple to a physician, and then the stresses multiply.

Stage 3 / Part 2: Diagnosis. The Balance is Shaken.

Once the alarm has sounded, the couple seeks out help from their physician. Every caregiver was able to share something about the medical encounter when the couple was seeking a diagnosis. Usually, it was not the first physician who saw the care receiver to provide a diagnosis, but rather a referral from that first physician. All of the warning signs that have been building, cause the caregiver to push the care receiver to go to the doctor. This seems a simple event, but in fact, leads to major sources of stress for the caregiver.

In most cases, they visit the doctor as a couple, with the caregiver raising a list of concerns. Right away this signals a shift in the marital identity. Even in very close, mutually symbiotic relationships, spouses see their physicians on their own. However, these visits as described in the interviews are usually made by both members of the couple, with the well spouse asking the questions.

This dynamic of the obviously symbiotic couple showing up for the appointment produces many startling medical interactions, perhaps because having both members of the couple present is unsettling to the physician. At any rate, an assertive well spouse seems to be the trigger for an unexpected finding of the research. As sometimes reported by the well spouses, physicians, nurses, even social workers find this questioning by the well spouses a source of distaste, and often, their response is to patronize or insult the well spouse, thus becoming an added source of stress for the caregiver, leading to anger, accusations, and a critical loss of time in the proper care of the dementia patient. (See Chapter 6 for more about this finding.)

Why does the well spouse intervene at this point? In some of the interviews it was clear that the well spouse doesn’t want to go to the appointment, because he or she doesn’t want to perform a kind of “parenting” role, yet hasn’t been satisfied with the results of previous appointments. The care receiver would return from these appointments without answers, adding to the caregiver’s stress, and postponing any possible treatment for the memory loss, or bizarre behaviors witnessed by the well spouse. In some cases another year would pass before the well spouse finally gets some answers. As Rita (I-5) shares: “That was the sad part. Because I was watching this happen, and I knew something was wrong. And yet if the doctor is shrugging you off, you know, as if you are making all these symptoms up. . .”

Enough has changed already in the relationship, so that in the majority of couples, the well spouse feels it is incumbent on him or her to be present for the doctor’s appointment. The employed caregivers often take off work in order to be present to get some answers. Of course, dementia is a disease that is difficult to diagnose, so the answers are not often forthcoming. The well spouse has to settle for a global diagnosis of dementia (probably Alzheimer’s), and a referral to a specialist, usually a neurologist.

Many of the caregivers, especially the men, balk at the lack of information. They want answers, explanations, prognoses, treatments, and instead usually leave with a prescription which may or may not work. They are also told to contact the Alzheimer’s Association. The word “dementia,” or “Alzheimer’s” now hovers over the couple, but there is no arsenal of weapons to battle this disease. The couple leaves this encounter without a strategy, almost in a vacuum, and it is no wonder that they often lose their bearings at this point. Rita (I-5) says she cried for days, and that this was her “sad” time.

The medical interaction at the time of diagnosis is difficult for the couple to experience in the best of situations, and frightening in some of the extreme cases. Poor Betty (I-23), 79 at the time of the diagnosis, is told by her physician, “I suggest you sell your house as soon as you can.” Kay (I-19) is very upset at the physician’s office because she clearly sees her husband’s serious cognitive loss, where at home he could mask it. “I think my big revelation … he wanted me to go with him into the doctor’s office which I think is hysterical as a grown man … he wants me to go all the time. I went and sat through two days of psychological testing and what he could and couldn’t do was astounding to me … I think I knew then.”

In some of the cases, the physician uses the mini-mental test, a short and somewhat controversial diagnostic tool, on the spouse experiencing cognitive changes. The dynamic of the symbiotic couple makes this painful for both. It is often the first time that either of them is aware of how much cognitive ground has been lost by the care receiver. When he or she cannot say where the hands go on the clock, or who is the president, they get very frustrated, and even angry. The well spouse wants to help, seeing this stress on the care receiver. Just as the caregiver has been unconsciously finishing the spouse's sentences, providing answers, filling the blanks in their shared social intercourse, he or she now wants to help ease the care receiver's frustration during the mini-mental test. This is what symbiosis is all about. The stronger member wants to buoy up the social identity of the weaker member, thus keeping some balance in the couple identity.

These dramatic events reveal not only what the dementia patient has lost, but what the couple has lost. Mutually beneficial symbiosis now is clearly threatened, if not completely gone. Here is where the "looking glass self" described by Cooley (1918) and Mead (1956) becomes conceptually relevant. The "looking glass self" is our self concept based on others' evaluations of us, as we perceive those evaluations. Clearly, the dementia patient can no longer mask his/her inadequacies; nor can the well spouse mask the inadequacies of their marital partnership. Everything is changed because everything is revealed.

Stage 3 / Part 3: Post Diagnosis -- A Time of Transition

What follows the diagnosis is the period of adjustment. Now that all the masks are gone, the symbiotic couple must renegotiate their marital patterns, and their individual identities. This is transitional, and there is a lot of open conflict during this period. First, they have to redefine themselves to each other; then to their families; and finally to their greater social milieu. Each of these new social identities brings reverberations in the form of questions, challenges, and denials.

A. Changing Sense of Self Identity: I am a Caregiver.

As is true of most transitional periods in adult lives, there aren't many guidelines for this navigational point of change. Everything about the couple identity is shifting and this instability tends to bring out emotional behaviors from both partners. This experience is not one they had expected in the marital trajectory. Most do not have a model to go by. But this is the time when they do know everything has changed. **The caregivers interviewed can almost always remember when they knew their identity had changed from partner and spouse to caregiver.** For Maggie (I-11), the shift in identity occurred as her spouse, the “sharp dresser,” the man 16 years her senior, that she had just married, began to wear miss-matched clothing. “But he began to wear outfits that I felt were not him. That was a shocking sign to me. . . .that’s when I knew.”

For Sarah (I-12), the sign of the transition to caregiver was much more tangible. “Truthfully, it was sex . . .there wasn’t any anymore …and I realized that that life is over.” However, she goes on to say that she actually felt sorrier for him than for herself, because she knew it was important to him. Similarly, Millie (I-13) knows how important the truck is to her husband, and now, she would have to “wake up . . .this is your baby…”

Will (I-17) was still at the very early stages of caregiving when interviewed, but he knows from the physicians, the social worker, and the support group that he is losing his wife. “I’m getting a shell.”

Activities of Daily Living (ADLs) are often a stimulus for sensing the changed identity. Betty (I-23) knows she is the caregiver because she has to go into the bathroom with her spouse. She has to tell him to wash his hands. Christine (I-28) knew she was the caregiver when “I had to put his clothes on…the shower, the toileting.” Note that this matches the highest stress time period brought out by the New York Caregiver study (Farberman et al., 2003).

Thus, ADLs, sexual expression, problems with driving, and sometimes physical and verbal abuse tell the caregiver, the partnership is changed. The realization of this changing identity begins in the physician’s office, but often is not really understood till later. The transitional period is a time of negotiation. The caregiver knows he/she has to become more responsible, perhaps more assertive. The caregiver roles demand new skills, skills that must be honed by the caregiver alone, without much support from the dementia spouse. What is happening to the care receiver is less clear from this research because the interviews did not include them. They know there is a change, and they express their feelings in different ways. From the interviews, there are only the perceptions of the caregiver to work with, but one of the questions in the interview guide did concern when the caregiver thought the care receiver knew that one of them had become the caregiver.

Most of the caregivers are able to say that the care receiver does know that he or she has a caregiver. Again, the signs include giving up driving, wanting the well spouse to handle the checkbook, not questioning the well spouse's actions, allowing the well spouse to assist with ADLs. For Lawrence (I-14) the moment of the realization proved to be quite poignant. "I think maybe it concretely came into focus when she asked me what was wrong with her. . . It was a very emotional moment for me because we were both crying … standing right here in the living room." Lawrence can visualize this scene so well because it marked the change for both of them. She was still able to ask, and he had to answer.

Rita (I-5) describes the early days after the diagnosis as very difficult for her spouse. "And he, he was in denial. In fact, when he got the diagnosis, he walked out. He said something like, 'He's an idiot. What does he know?' And he just walked out, walking around the parking lot. I came out, and you know, he was angry. He was angry at me. Because he said, you know something like, 'You, it's your fault!' I said, 'No, it's not my fault. It is a disease.'"

The same angry response is expressed by Moira's (I-6) husband, when the neurologist tells him he cannot drive. "He went berserk in the car. I 'shouldn't tell anybody these things, you have no right to do that! You know this is what I want to do.' And I said, 'Well, it is not you. It is for whoever else you hit.'" Abby (I-31) has a similar experience. Again the neurologist tells her husband he cannot drive, and later he accuses his wife: "You took my manhood away!"

Notice that, in those examples, the care receiver blames the caregiver spouse. For the men especially, this is the pattern. There is so much anger. Many of the caregivers describe a personality change, where their once sweet, good-natured spouse is suddenly "ranting and raving." One describes being inside her home, and the spouse, "all day irritated." Another says that her spouse had a short fuse, but "it got shorter and shorter." Where one gentleman had always been a tease, he began to purposely irritate family members. Another one, who had shown some earlier prejudice, began cursing and using ethnic and racist slurs on a regular basis, making the caregiver miserable.

Where does this new angry identity come from? If we consider that one of the steps in learning to accept a diagnosis is “Why me?” then, indeed, the anger is easily explained. The dementia spouses have received essentially a death sentence, but one that will progress slowly, at the same time robbing them of themselves. Perhaps the men experience more anger because they may be used to having more control in their lives. Having dementia is all about losing control.

Even the female care receivers grew angry and agitated as they saw their control slipping away. Relocating at this critical period was especially challenging to two of the care receivers. When Dan (I-30) moves his spouse out to California so that they can be near a daughter, she is agitated and unhappy. He then reverses that decision, realizing that the new environment was too stimulating for her. She needed the comfort of home. In the second case, it is a male who is angry at relocation. Judith (I-9) buys a new house with her daughter and son-in-law, so that they can live together, making future caregiving a little easier for her. But her spouse doesn’t understand this, and accuses all three of them of lying to him and not telling him this was planned.

Does this pattern of angry response from the caregiver continue at that level? No, in most cases the anger is part of the transitional time, but it could resurface, especially for some of the care receivers.

Because of the change in competency on the part of the dementia spouse, many of the caregiver spouses speak of their need to become more assertive. One of the caregivers uses the word “caregiver” to actually let the dementia spouse know that he has to defer to her on the topic under discussion. If he didn’t want to take a new medication, she would say: “You know you have appointed me as your caregiver, like it or not, you can always change it to Charlene any time.” The Charlene that is mentioned is the spouse’s sister. Sometimes she uses the name of his ex-wife. Both of these alternative choices must not be appealing, because he will then defer to his wife. It is her subtle way of threatening him. If you want to depend on me for everything else, then you have to defer to me as well.

Another female caregiver describes her new role when she says: “I make rules.” But this assertiveness is a new role for her, as it was for most of the female caregivers. The cohort of caregivers in their 70’s and 80’s often expressed that being a caregiver wasn’t really a new role, just the assertiveness. Being a caregiver was what they had always done, what their mothers had done. Lucille (I-35) says: “We were brought up that you catered to the man in the house. You do it without thinking.” Kitty’s (I-26) children berate her for doing too much for their father, but she has always done this.

Thus, for older female caregivers, the transition at this point to viewing oneself as a caregiver is a little smoother. Nineteen of the 40 caregivers had prior caregiving experience, usually for a parent. (Note: This figure does not include the normal caregiving by both parents while raising children.) Of the 19 experienced caregivers, only two were male, and those two males had disabled children. Two of the remaining male caregivers in the interview sample, also had prior experience caring for their wives. In one case, the wife suffered from depression throughout most of their married life. In the second case, the wife developed a disabling chronic condition earlier in the marriage, and then went into remission when the dementia process began.

Not only did the females have the prior caregiving experience, but all of the female caregivers were mothers. They had been the primary caregiver for their children, although in one case the children were her stepchildren. All of the male caregivers were also fathers, but their role in the family was the more traditional role of provider, especially the older males. Most of them commented on how much their wives did in the raising of the children. All of this is to emphasize that the transition to viewing oneself as the caregiver is not so hard for the women, with one important distinction. Most could see themselves nursing a sick husband, but what was so new and unsettling was losing who that husband was. They ultimately will be providing care to someone who may not recognize them, who cannot communicate with them, but who is attached to them as firmly as a mussel on a rock. However, at this stage, they can accept their early recognition of what a caregiver is.

The men do not come to the role as naturally, mostly owing to their prior experience and social conditioning, and some actually develop a different language for the new identity. Earl (I-16) calls himself "the sentinel." He explains that he does not sleep well at night because he is his wife's sentinel. "I'm the sentinel. I'm alert." He also makes sure the doors on the house are locked, because she will wander. He locks parts of the house. When she fights this, he tells her that the police asked him to do it.

Another control-oriented caregiver, Doug (I-18) views himself as his wife's protector. "I'm a light sleeper now because if she gets up … I don't want to be a deep sleeper anymore." Furthermore, he won't order the "Safe Return" bracelet marketed by the Alzheimer's Association. This ID bracelet is simple for a care receiver to wear, and can relieve some of the anxiety for the caregiver about spousal wandering. But Doug won't get one of those bracelets, because in his mind, this might cause him to let down his guard, and he can't accept that as a possibility. He believes that his new identity is to be her protector, around the clock.

Most of the men see themselves as becoming the proactive caregiver. Their image of themselves is also an extension of a male role they have probably acted out for a long time. They must think ahead, plan, be on guard, research, hire help if necessary, and stay strong. This is what a man in their situation must do. What if he cannot do this? What if others must step in and do this for him? That happened to one of the older male caregivers, 85-year-old Eddie. His evaluation of himself, due to his inability to really protect his wife, is, "Rotten Eddie."

B. Changing Social Identity within the Extended Family

During the transitional period, the couple must also alert their children, and show their children their new identity, both as individuals, and as a couple. This tends to be another reason for the turbulence of this stage. This is the first venturing out into the social world beyond the symbiosis. How will the children view the changed identity of both their father and their mother? Will they support the caregiving function? Will they argue about the diagnosis?

Since all of the caregivers had children, there were many references in the interviews to adult children. Adult children fall into two categories: near and distant. For the day-to-day support of the caregiver, near adult children are optimal. However, many adult children are near but not supportive. These distinctions seem to affect the caregiver very early in the transition.

There were many similar perceptions of adult children during the interviews. Generally, these caregivers tended to have more than one or two children. Many of these dementia couples were part of the post-WWII couples who parented the baby boom generation, so they often had four to five children. But in most cases, there were children at a distance. Children at a distance tended not to be as responsive to the changes in the dementia parent. They either were not aware of the changes, or they used their distance to deny the changes. Although this cannot be said of all adult children at a distance, this was the general experience of most of the caregivers interviewed for this study. Is there something about the distance itself that works against healthy support for the caregiver? Primarily, the distance seemed to buffer the adult child from the reality of the day to day changes in the parent. If the child was also very involved in his or her own personal and professional life, the buffering was very helpful. When they did hear from the caregiver about problems, they often responded with impatience, in some cases even bullying the caregiver.

Judy (I-9) is one of those caregivers with a large family, five adult children. Her oldest daughter is the most resistant to the idea of a change. “It just can’t be, Mother. Nope it is not going to be.’ And I said, ‘Well, what is, is, Michelle, and we can’t change these things.’ She still hasn’t quite. ..she doesn’t know how to handle it.” Judy has another child, her son, who also lives at a distance, and his response to the diagnosis is that it cannot be Alzheimer’s, but may be Parkinson’s. These denials would be very hard for Judy, if it weren’t for her nearby daughters, who are much more in tune with the change, and immediately looked for ways to support their parents.

Lawrence (I-14) has two adult children, one close at hand, but the other in California. “My daughter was more emotional than my son. He’s not here. He’s there. She’s here and she’s been very involved with her mother all these years.” Another male caregiver, Dan (I-29), says the same thing about his second daughter. “She doesn’t quite realize what the every-day situation is.”

There are other reasons suggested for why certain children in the family have trouble accepting the diagnosis. Often the caregiver says that the adult child in denial was also very close to the dementia parent. Amy (I-1) says “My children also, especially my youngest son, had a great deal of problem accepting that this was happening to him. He had the most trouble. I think partially because he was very close to his father. . . : He saw it. I believe he saw it. He just was denying it.”

Wayne (I-34) declares that his one daughter is in denial, while his other daughter is very open and agreeable about the situation. The one in denial is not only distant, but she is emotionally closer to the mother. The open, agreeable daughter is the one emotionally closer to him and nearby.

Furthermore, adult children who had problematic relationships with the dementia parent are very likely to remove themselves from the situation. Previous dysfunction in the family almost guaranteed that the children would not be very supportive, unless there was one parent they cared about.

An interesting pattern in the second marriages, was how the caregiver’s children treated the dementia spouse, who was in fact, a step-parent. In the few cases included, these children were much more supportive, than the natural children of the dementia spouse, perhaps because they were trying to rally behind their caregiver parent. They continued to visit regularly and intervene when the caregiver needed support.

Another curious twist was the support many caregivers received from sons-in-law and daughters-in-law. Their own adult children might be in denial, and somewhat antagonistic, but the caregiver often sensed support from their children’s spouses. In some cases, it was the son-in-law who physically came to the aid of the female caregivers.

Distance also causes some adult children to become very concerned about both of their parents, to offer more advice and solutions than the parents may want. In their removed situation, where they cannot intervene, they can still worry. However, this worry often becomes overbearing to the caregiver, resulting in more stress. A female caregiver described this as giving pointers from “her point of view, not mine.” One caregiver’s son called her almost every day, trying to make sure his mother was all right.

(The dementia parent was a step-parent in this case.) These distant children are very worried about the situation, but from a distance their concerns are often adding stress, rather than alleviating the stress.

The adult children nearby have a much more significant role to play, because they can see firsthand what is happening to their parents; whereas a caregiver might not share everything with a child over the phone because they are busy, and she or he doesn't want to worry the adult child. Thus, the near child will react and the caregiver spouses will have to process this reaction. For example, if the near adult children go into denial, and accuse the well spouse of making it up, always looking for something wrong, "always bitching about something," the sense of isolation for the caregiver begins to set in.

A common description of the adult children and their families by their parents was "how busy they are." This perception of the world of the adult children tends to make the caregivers keep information to themselves. Most of them, male and female, did not want to burden children. All of this leads to the increased isolation not only of the individual spouses, but of them as a couple. It is this isolation which grows deadly as time goes on, intensifying the symbiosis and causing it to grow unhealthy, even toxic.

C. Changing Social Identity in Their Greater Social Milieu

Besides alerting children and other family members to the changed situation of the couple and their new roles as caregiver and care receiver, the couple must also navigate their larger social milieu of friends, neighbors, and sometimes, co-workers. The interactions with that world will be changed as well, and all of these changes and adaptations will have to be navigated by well spouse and dementia spouse, as well as those in their social network.

First of all, the couple has to decide who to tell and secondly, who does the telling. Does the caregiver tell friends and neighbors, or does the care receiver? In the interviews for this research, it was more common for the care receivers to tell friends, once there was a diagnosis. However, owing to negative stereotypes about dementia, the care receiver sometimes met confusion and embarrassment during that interchange, thus making it less likely that he or she would continue to be so open. According to

Phil (I-40), ". . . at one point she said, 'We'll fight it, don't worry, we'll take care of it,' and she was very positive about it. She was telling everybody … 'I have Alzheimer's but don't worry, I'll be ok.' Little by little you would see it was eating at her and became a little more real. . . It changed to where … 'I'm not going to tell anybody.'" This is a perfect example of symbolic interaction at work in changing the social identity of the care receiver. Phil's wife tried to be open about her condition, putting on a show of optimism for others, but in seeing their reactions, learned that such optimism was not well received, modified her behavior, and retreated into hiding.

Another reaction that a care receiver might get from a friend is denial of the reality. Karen's (I-2) spouse told his friends about the diagnosis, and most accepted it, but for one. This male friend insisted that the cognitive and memory lapses were "just his age." This upset the husband. He wanted acceptance from his friend, not denial. Karen says her husband "went through a bad time" over this.

These two examples point out how friends can quickly squelch the optimistic mood of the dementia spouse, seeking acceptance. The same looking-glass effect can be seen in the caregiver who shares the diagnosis with a friend. In Laura's (I-10) case, she reconnected with a friend who had also moved out from the City to suburbia. The friend wanted to get together, but after Laura revealed that her spouse had "the A word," she didn't hear from the friend again. When she contacted the friend herself to set up a lunch date, the friend told her, "I'll call you. Don't call me." And Laura never heard from her again.

Most of the stories related by the caregivers in the interviews were more positive than these. Long time friendships usually survived this change in the couple's life. If the couple has lots of couple friends, then the men tended to look after the male care receiver, making life considerably easier for the well female spouse. Restrooms in particular are a source of stress for caregiving spouses, and friends who can assist the male or the female during the use of a restroom, are truly lifesavers. Sometimes, caregivers are so stressed by the restroom challenge, that strangers step forward and offer to help. They see the worry on the face of the well spouse, and step up. These were coded as "guardian angels" for that is how the well spouse saw them. They showed up on cruise ships, in Broadway theaters, on airplanes, and in medical facilities.

The behaviors of the dementia spouse do, however, sometimes constrain the well spouse from engaging with friends. In Earl's (I-16) words: "My kids say you should go and see your old friends but then I feel…I feel sort of embarrassed by the whole fact even though they're our friends since we were kids. . . I feel funny bringing her. She steals things. She'll pick up something and take it. We almost have to search her before we leave anywhere. That's embarrassing. It doesn't bother her but . . ."

Amy (I-1) won't go to parties in her housing complex because her spouse will try to eat off of the serving plate. "I don't want to embarrass him by having him do that in front of people, and I don't want to have to say to him, 'Don't do that!' . . .It is hard. You would rather not do it." Annalise (I-20) also shares that she and her dementia spouse stopped going to social functions because they were "a bit less than an entertaining couple" and people want to be with "entertaining" couples, so "we socially withdrew."

Many of the spouses have always found neighbors to be supportive, and in half of the stories that is still the case. But for some of the caregivers, neighbors have changed and this has introduced a new set of problems. Martha's (I-33) husband was friendly with a neighbor across the street, but that family moved. "One day this young man comes to my door and says he bought the house across the street and my husband scared the hell out of his wife one day. He (dementia spouse) went into the house looking for somebody (his old friend.) 'Don't you dare let him in the house again.'"

The tendency to out-live and out-stay one's friends and neighbors leaves many dementia couples relying on phone calls for support and validation. They seek out people who knew them in happier days, and very often these friends are supportive. If they come to visit however, or invite the dementia couple to visit, this reassurance can be shaken. Amanda (I-25) had friends in Florida who came to visit and from that point on, were less "tolerant," and haven't renewed their request that she and her dementia spouse visit them in Florida. Martha (I-33) describes friends who have disappeared, who "just can't take the stress or feel uncomfortable." And Kay (I-19) describes two friends who disappeared from her life after her spouse's diagnosis. "It still bothers me. (Those) Who

I thought would be there to the end and they just totally disappeared . . . (because) it's too needy a situation."

But for those caregivers who have moved to senior communities, there is a little more neighborliness. Amy (I-1) loves her development, because her neighbors watch out for her husband. They call her if they see him go out by himself. And one of them asks her if he could ask for her dementia spouse's help if he needed help moving something. The male neighbor says, "It would be good for him to do that." Abbie (I-30) lives in a senior community, where she has made friends with the neighbors. One of them listens to Abbie, 83, and lets her cry. The neighbor tells Abbie that it will get worse, because she went through it with two family members, but she tells her, "I'm here to help you."

What makes some friends and neighbors supportive and others not? Perhaps it is their own "identification" with the situation of the couple. Certainly, many of the men who come forward to assist the male dementia spouses are concerned about the dignity of the male spouse. Fewer women seem to come forward, and when they do, can get frightened off. They want to support their female friend as well, but are somewhat fearful around the male dementia spouse. Women will step up though and take the female dementia spouse, giving respite to the male caregiver spouse. Most of the males interviewed did have female friends who offered to take their wives. Rarely did female caregivers get these offers, especially from women.

By way of exception, Christine (I-27) did get a visit from a close female friend who lived in New Mexico. Since Christine was still working, the friend and the dementia spouse would go for a walk, and then she would fix lunch for him. One day, the well spouse got a call at work asking her to come home. "C. had an accident. I've got him in the bathroom, but I can't do this . . ."

Thus for most of the caregivers, the new life stage is one of increased isolation, one they have to navigate mostly on their own. As Phil (I-40) says at the conclusion of his interview, "We have no real social friends at this point which is a downer and that brings up the stress level also. If I need a favor I can't just call somebody and say come over. The couple across the street died. One moved away. The people next door are selling their house, (and) they live somewhere else now."

Except for the couples who had moved into senior housing communities, the external circle of friends greatly diminished for various reasons. Sometimes the relocation of the couple, or of their neighbors created the change. The working caregivers did not have time to maintain outside relationships. The older caregivers, those past 75, often did not have transportation or time to connect with friends. Even those who had many friends before, either through church, organizations, or work, tended to lose track of those connections owing to relocation, or simply choosing to withdraw, perhaps out of fear of being cut off. The major exception was that group of couples who moved into senior communities. Their new neighbors often were supportive to the couple. There were also a few respondents who had strong social connections with other couples, and a few of these connections withstood the test of dementia. In one case, the caregiver's female friends also had husbands who were developing dementia. They began using the computer to stay in touch.

All of this change in relationships further modifies the caregiver's social identity, and further seals the growing symbiosis. What began as budding dependency, grew into significant role changes for both caregiver and care receiver, with the resultant changing social identity. At the beginning of this chapter, the couples were seen interdependent, in a mutually beneficial symbiosis (Stage 1). However, the symbiosis moves into its second stage, the stage of pre-diagnosis, as the disease of dementia began to take hold (Stage 2). Subtle signs of change manifested themselves, usually pushed back by denials of silence from both spouses. This joint conspiracy continues as long as it can, until some kind of alarm is sounded, and the couple knows all is not well. This alarm causes enough distress and uneasiness to warrant an appointment with a physician (Stage 3/1), and ultimately, the diagnosis (Stage 3/2). The diagnosis abruptly pushes the couple into transition, marked by an obvious role reversal, from normal interdependency to a one-sided dependency (Stage 3/3). Everything about this transition is upsetting, as individual identities have to negotiate new roles, new definition.

In Chapter 4, the fourth stage in the process of changing symbiosis begins, a time where the couple's new identity is clearly marked by one spouse's growing dependency on the other. Not only are they aware of the changed nature of their relationship, but their entire social network is also aware. And as the transition pointed out, there will be more withdrawal, more isolation for the couple, who find themselves engaged in a dance just for two.

CHAPTER IV: STAGE 4 OF SYMBIOTIC STAGE THEORY

Stage 4: Commensalistic Symbiosis. The Couple Goes Within.

The second major period of the couple's movement through the stages of their symbiotic dementia relationship resembles the type of biological symbiosis called "commensalism". Biologically speaking, symbiotic commensalism occurs when the two organisms living together no longer mutually benefit from their linkage to the same extent. The stronger organism is now the host organism, and the weaker organism is dependent on the relationship with the host to survive. However, the relationship is not injuring the host at this point. Rather, the relationship is now imbalanced, with one strong organism and one dependent organism.

Extending this metaphor to the dementia couple, this is the stage in the caregiving relationship that becomes a holding pattern for the couple. Their trajectory as a couple is still downward, but day-to-day, the couple survives, symbiotically. Most couples spend several years at this point, and a few spend up to a decade. They all tend to live by themselves, without other family members present, except for the younger caregiving couples interviewed, who sometimes had children living at home.

This stage in the dementia couple's story is somewhat stable, because both caregiver and care receiver are aware of their situation. The dementia spouse knows he or she needs someone to depend on, even as their disease progresses and they sometimes do not recognize their spouse. The caregiver knows he or she is responsible for both roles in their marriage, because the care receiver will progressively not be able to enact the role he or she previously played. Furthermore, there is the prospect that the dependency could become deleterious to the host at some future time.

Although this stage could continue for many years, if the disease accelerates, and support services aren't in place, the caregiver will start to both physically and mentally suffer from the demands of the caregiving role, and from the strain of the increased responsibility. But for Stage 4, the couple is indeed "sharing a table" the direct translation of the Latin roots for commensal, *com mensa*, and it is a table for two. Their symbiotic attachment has been altered from one of equal footing, to an attachment where one spouse must be stronger, more responsible, dominant. The other must hold on in order to continue functioning.

The interviews elicited information about the symbiotic couple identity, and generally found many verifications of the commensal symbiosis. Moreover, some of the axial coding showed the undeniable causes for the commensal symbiosis; some showed behaviors documenting the commensal symbiosis; and some showed outcomes of the commensal symbiosis. Each of these dimensions will be explored.

Causes of the Transition to Commensal Symbiosis

Most of the causes pertain to some aspect of the care receiver's diminished cognition and judgment or to his/her growing dependency. Each of the losses experienced by the dementia spouse pushes that spouse closer to the caregiver, increasing the dependency, and strengthening the symbiotic coupling.

1. Health of Care Receiver

Most of the caregivers had assumed the role of health guardian for the dementia spouse. Especially where the care receiver is older, there are usually other health issues that the caregiver must consider, setting up necessary appointments, escorting the spouse to the appointment, often speaking for the spouse at the appointment.

Caregivers also usually control and dispense the medications, because almost universally, the care receiver does not remember anything about medications. The number and variety of drugs taken reflect the recommended drugs for dementia, as well as for other conditions affecting the care receiver. Many care receivers take psychotropic medications that relieve anxiety and/or depression Those who have sleep disturbance issues, may take sedatives. Finally, there are the other medications necessary for age-related chronic conditions, especially heart and circulatory diseases. All of these drugs can interact with each other, and can cause noxious side effects. None of them cure the dementia, though some do seem to slow it down. If anything about health care pushes the well spouse into an even greater responsibility for the dementia spouse, it is the plethora of drugs, and the danger of using them incorrectly.

Next, there are the watchful, observant behaviors of the caregiver, which function to protect the care receiver from strokes, heart attacks, falls, diabetes. Amy (I-1) is a good example.

> And I noticed his gait, his step, his balance is not as good anymore. I am afraid of him falling. And on top of that right now, I have to take him to the doctor's at 3:30. The past week, twice that we walked, he had shortness of breath. Actually, the worst was Thursday. And he came in, he was leaning on the wall. I noticed he was sweaty on his forehead.

These watchful behaviors are common in the interviews. Many of the well spouses worry because their dementia spouses don't eat enough; eat unhealthy food; don't have any interest in walking; are gaining weight. These topics frequently came up in the interviews.

Another stressful aspect of care receiver health is what happens when a medical procedure must be performed, whether it is routine, or an actual surgery. Lawrence (I-14) experienced this when his wife contracted a urinary infection.

> She had a urinary tract infection about two months ago. We didn't know it until she went to the doctor and he suggested a blood test and the blood test showed it. Another thing, you try to collect urine. You can't collect urine. In the morning when she has to give urine, I take the pad and I squeeze it into a container. That's the only way to get urine. They have all sorts of gimmicks. They say you do this or do that. I say I can't. They don't seem to realize that this woman can't stand, she can't respond to a request …

Even more significant is a hospitalization, because the care receiver usually does not respond well to the new environment. Several caregivers described the extreme behaviors of their spouse in response to the change of the environment, absence of the well spouse, and in some cases, to the dementia spouse's own medical condition. These public episodes will be described further along, as will the stress of the medical interaction for the well spouse, but even when there is a supportive medical environment, the separation from the well spouse is very hard for the care receiver.

Matt (I-3) attended a wedding with his 85-year-old wife, and at some point she fell, as she tripped going up the steps. Fortunately, there was a nurse present, and his wife regained consciousness, but was bleeding. Therefore, an ambulance was called, the hospital admitted her, and an aid was assigned to her around the clock, so she wouldn't get out of bed. She was disoriented most of the time. When Matt tries to leave, she tells him, she is coming with him. Matt tells her that she cannot go with him, and that she still needs more tests. "I'm going. I don't care." This is where the caregiver practices "creative lying" which they actually teach each other in the support group. Matt tells her he just has to go move his car, and leaves.

Every aspect of the dementia spouse's health tightens the attachment to the caregiver. The caregiver must oversee and guide, sometimes drag, the care receiver to doctor visits, medications, healthy living. Every hospitalization is a challenge because the stability of the dementia spouse is upset, and since dementia patients are difficult to treat in hospitals, more damage can occur. Small strokes, electrolyte imbalances, failure to administer necessary medications for other conditions, can all cause further decline in the care receiver.

2. Care Receiver Lack of Mastery

The care receiver's declining abilities lead to several complications for the caregiver. Almost always the caregiver mourns these losses in mastery, even where there isn't much affection between the two. The majority of caregivers respected certain things about their spouses: their engineering skill, mathematical ability, computer ease, cooking mastery, propensity for fixing things, avid reading interests, political interests, love of the outdoors, charm in social situations, intellectual prowess, love of children. In other words, the caregivers acknowledged and usually prized those bright spots or strengths in their spouse's identity. Many times these are the very traits they fell in love with originally. Yet, these are also the very attributes that dementia first weakens, then wears away, and finally destroys, as it destroys the mind of the dementia spouse.

What remains of these attributes is in the mind of the caregiver, and some of them become the "keeper of the flame." These interviews are full of reminiscence stressing the competence and sometimes brilliance of the care receiver. Clearly, the dementia partner is pulled in closer for the well spouse to protect. The bonds of symbiosis are definitely powerful for these well spouses.

If lack of mastery highlights past excellence, it also points out a new vacancy in the relationship. When the dementia spouse always did the checkbook, always handled the investments, always prepared the meals, always took care of the automobile, always did the laundry, always took care of the yard, etc., who will do it when he or she cannot? Someone has to fill the vacancy and few of the caregivers could afford to hire others to do these things. Some of the greatest stress expressed by the caregivers came out of the myriad of tasks bearing down on them. What symbiotic married couples often do is split up the chores, building on their personal like and dislikes, or on socially determined roles. These dementia couples were mostly in later life, very much products of their cultural upbringing, so it is no surprise that the men struggled with the cooking and cleaning, laundering, and shopping. The women were challenged most by the periodic home repairs and the maintenance of the car and yard.

Sometimes the lack of mastery in the care receiver affects his or her outward appearance. This is upsetting to both the male and female caregivers. Many of the men speak of laying out their wives' clothes. Mike (I-18) says his wife will wear the same thing over and over again, if he doesn't lay out her clothing. Another spouse shares that he gets out pajamas for his wife at night, but after undressing, she hides her underwear. When he asks her about it, she says, "I have to keep that for tomorrow morning because I don't have any more." So then he looks for it and usually finds it rolled up in her jeans. He then substitutes a clean pair the next morning, so she doesn't know. These are intimate details of spousal caregiving by males, tasks they do every day to support their weakening wives.

Less surprisingly, the female caregivers also closely watch the appearance of their spouses, laying out clothes for them and making sure they look alright when they leave the house. What they also tend to do is make light of the obvious lack of mastery, whether it is choice of clothing, use of a tool, or failed attempt at a task, and this appears to be out of respect for the dignity of their husbands. Amy (I-1) found her spouse wearing not only his shirt, but her pajama top, which she had left lying on the bed. Her first response is laughter, but a gentle laughter, followed by a quick “let’s fix this” response.

Appearance and dignity both point out the motivation of the caregiver who undertakes damage control, averting some of the undesirable effects of a socially perceived stigma (Goffman, 1963). Their couple status means that not only are the caregiver spouses preserving the dignity of the dementia spouse, but their own dignity as well, as part of the dementia couple, again emphasizing the symbiotic nature of their relationship. As the dependency increases, the attachment tightens, and the “spillover” effect increases.

Some caregivers do not have the same ease of dealing with the lack of mastery. The most difficult challenge reported by a majority of the caregivers is to maintain one’s patience, and certainly it is caregiver lack of mastery that tests patience. Lack of mastery was the third most frequently coded attribute, after caregiver stress and couple history. So much of the story related by the caregiver is really about what his or her spouse has lost. Thus this attribute of lost mastery is somewhat key to any resulting theory, and as was shown above, accounts for the ever increasing role change. It is no longer a role-reversal, because one spouse is really giving up all roles incrementally, while the other is forced to assume those cast-off roles. This clearly is related to changing identity, both for the individual and for the couple.

3. Care Receiver and the Driving Issue

It should not be surprising that if the key rite of passage in our culture for growing up is getting a driver’s license, then giving up the license becomes the most contentious loss for the care receiver. Dementia spouses generally do not give up the keys to their cars, willingly, although this did show up in a few of the interviews. Kitty’s (I-26) husband, 89, gave up driving voluntarily at 79, because he always had said he would. At that point, he already had been diagnosed with a dementia, so his decision was beneficial, except for the fact that Kitty does not drive. An urban girl, she had never learned to drive, and therefore is mostly at home. Her spouse goes out to adult day care, but she only goes out for necessary trips, and for that, depends on her family.

Millie's (I-13) spouse also gave up driving (as described earlier) while he still was working, and never explains why to Millie. She knows something must have happened, but they never spoke about it. Doug's (I-18) wife turned over the keys to her husband on her own, and told him she thought they ought to sell her car. In all of these cases, the dementia spouse must have experienced difficulties driving, and chose not to deal with that stress given their declining capabilities. Fortunately, in most of the cases, the well spouse could and did take over.

Those are the easy cases, where the care receivers know enough to realize that it is no longer safe for them to drive. They actually reduce their stress by turning over that responsibility to others. However, the majority of care receivers do not go through this transition willingly. Most fight this change more than any other. In fact, of the 91 times Care Receiver Driving was coded, 57 times it co-occurred with Caregiver Stress. The driving issue is not only challenging to the dementia spouse, but also to the well spouse.

In a few cases such as Laura (I-10), Nora (I-24) and Grace (I-38), the challenge is that they, the caregivers, do not drive, or do not feel comfortable driving. Thus, they not only have to help their spouse give up driving, but know all the while that this will increase their own burden. This is further challenging because it increases their isolation, since they will not be going out as often.

Again, in the majority of cases, the challenge to the caregiver is quite significant. They have to visibly, obviously, and definitively take the keys away from their spouses. In four cases of the forty interviews, this exchange marked when the well spouse believes the care receiver identifies him/her as caregiver. This exchange is one of the most definitive signs of change in social identity. The adult who is no longer able to drive in suburban or rural American culture is somewhat like a beached whale. Their vulnerability and dependency is obvious to all.

For some of the care receivers, this is not as big an issue because they may have been relying on their spouse for transportation for a long time. This is the case for some of the remaining female dementia spouses. Still, 17 of the caregiver spouses indicated that this exchange was stressful.

Christine’s (I-27) spouse experienced a progressive decline for 15 years. In the first five years, he still could function and was driving. They had retired to a somewhat isolated community. Somewhere after he turned 65, his son-in-law noticed that he had put the key into the radio to try to start the car. On another occasion he had hit all the cones marking lanes for entry onto a ferry. There also had been cases of sideswiping, so the family prevailed on this dementia spouse to stop driving. What followed was a period of intense anger and agitation. “For two years when I was driving, it was a nightmare . . . everything I did was wrong.” This is the thankless role that the caregiver spouse creates for herself (usually female for this scenario.) She becomes the villain. Every car experience is a time of extreme anxiety for the male dementia spouse, because he is out of “control” of the driving. The more closely the male identified with the role of driver, loved cars, etc., the more difficult this transition appears to be. In Christine’s case, her spouse had been an excellent driver, and although not argumentative previously, “always liked to be right.” She agreed that the issue was one of control, and it was very stressful for both of them.

In some of the stories, the male dementia spouse actually had a job involving driving, so identity was even more entangled with driving a car. Rita (I-5) was starting to see problems with her spouse, who at one time had a postal route. However, she didn’t push the issue with him until she got jury duty, and saw a case where someone was sued related to an auto accident. Then she had the conversation with her husband that she had been avoiding: “I saw what happens and somebody can actually sue somebody else. Now in this case, we are aware of the disease, and I will be at fault, because I am the caregiver. That is when we used the word caregiver. ‘I am the caregiver, and it is up to me to make that decision. It isn’t up to you.’”

Amy’s (I-1) husband also drove as a part of his last job. However, he hurt his knee, and had surgery, with Amy hoping that would be the end of the driving. “And then he said to me one day. ‘I am going to drive the car down the road.’ At this point I was hoping he would never drive again. And I said, ‘I don’t think you should do that. That knee is not strong yet.’ I argued, I argued. He was going. So he drove down the road, and he came right back. ‘See I can do it!’ But he never really drove again after that.”

Kieran (I-36) had to trick his spouse, because her cognitive decline was more serious than in the typical dementia patient. She did not know she shouldn’t drive. So he would give her the key to the car, but not to the ignition. She would go out and try to start it and be frustrated. In addition, he had the alarm on the car set to go off when she unlocked it. This frightened her. It caused her to vent her frustrations on him, which she did, and he said it took a long time before she stopped being angry about giving up driving.

There are cases where the physician tells the patient not to drive, that it is putting others at risk, including the well spouse, who may be sued if the driver causes a serious accident. This reasoning works well in the early stages, and in Alzheimer’s, but not as well with other dementias. If the dementia spouse has a bad experience behind the wheel, that also will help with giving up driving. Some stop because they get lost, or have a “close call.”

One unusual case involved Eddie (I-22) the 85-year-old caregiver. He himself had a serious accident with his wife in the car. The car was destroyed, and they were fortunate to come out of it. He does not have enough money to replace the car; they live in subsidized housing; she gets services, but he is somewhat stuck, a man without a car. He tells me that driving with his wife was the only activity they still shared. She enjoyed it. Furthermore, he doesn’t have male friends nearby, and his one dear friend, no longer drives either. Needless to say, Eddie might be in as much need as his wife. He suffers from depression and refers to himself as “rotten Eddie,” which he never explains.

In just this one case, the change in driving capacity actually is causing a nose-dive for the caregiver’s mental status. The issue of driving capacity should definitely be considered one of the mileposts not only on the dementia passage, but regarding the aging process in general. For this research, it is one more of the causes for the care receiver to depend more on the caregiver, and for the symbiotic bond to intensify. They have little independence from each other after this point.

4. Care Receiver Dependency

Dependency is not well accepted in American culture. Yet, commensalistic symbiosis, by its biological meaning, indicates dependency. Furthermore, as was seen in the prior discussion of the causes for commensalism, dependency is the outcome of the dementia progression. In the analysis of the interviews, every time the caregiver expressed a weakness in the care receiver, a need for the caregiver to step in and assist, dependency was coded. Not surprisingly, it frequently co-occurred with a coding for “caregiver identity” and “caregiver stress.” Perhaps part of the reason it is stressful is that it is unwanted in our culture. Most marital couples although interdependent do not like to see themselves described as dependent. Spouses do not expect that the other spouse will become dependent.

Thus, it happens that as the dementia spouse needs more care, the well spouse senses the dependency, and finds this stressful. Robert (I-4) describes his spouse as staring at him all day. When asked if she sees him as her caregiver, he says that she looks to him for everything. Needless to say, with this unending focus on him, he is at a high stress level during the interview. Amy (I-1) says that it is a 24/7 experience. If she has to put the garbage out, he starts crying out for her, because minute to minute, he forgets where she is. Sarah (I-12) also says that her spouse wants to be with her every moment, so that she feels she can’t even leave him to go to the bathroom.

Lena (I-21) is married to someone 14 years older, who not only has been her spouse but her mentor. She mourns this increasing dependency as she sees him check in the morning to see if her car is outside. He is anxious if no one is in the house with him, and when she offers to get an aide or a friend to stay with him, he says no. He wants her. Almost every interview shows evidence of this behavior, which really is something beyond the dependency that mobilizes assistance with ADLs. It is rather a dependency that reflects symbiosis. Dementia spouses want to stay home, and they want their well spouses to stay home. They don’t enjoy company. They watch their spouses while they work, and even while they sleep. They forget that a spouse tells them “I’m going out and will be back in an hour.” They have high anxiety until the well spouse returns. All of this dependency will come back to test the relationship in the last stages of the symbiosis. These are the warning signs.

5. Assistance with Activities of Daily Living (ADLs)

"Every once in a while he'd say, 'Can you believe this? It's like dressing your baby.' I'd say, 'But it's my baby, sweetie, so that's ok.' He'd laugh." This is one of the quotes from Jill, whose 89-year-old spouse died just a couple months before the interview. What made her and many of the other caregivers stand out was the tact and sensitivity that they showed to their spouses when helping them with ADLs. Jill's spouse did not have Alzheimer's but another form of dementia, and he didn't lose as much ground as some of the others, until the last months before his death. Her husband had been a military man, and perhaps that is why she understood his need for control over himself. She instinctively knew how to handle him.

In the world of dementia, activities of daily living include: dressing, bathing, toileting, feeding, and grooming. As the care receiver loses more abilities, he or she finds it impossible sometimes to accomplish these tasks. One of the first to go is the task of dressing. In order to avoid the decision-making involved about clothes, the dementia spouse just decides to wear the same thing the next day. They lose judgment about their own body odor or their dirty clothes. Thus, the next one that challenges the caregiver is usually bathing or showering. These two activities tend to over-stimulate the dementia spouse so they start to fear that experience, and again, avoid it. As with giving up driving, this is one of the most frequently cited problems that caregivers express.

Grooming is probably the next task that dementia spouses fail to do. Their caregivers must remind them to comb their hair, brush their teeth, files their nails, etc. Ultimately, they will have to model the action, because the care receiver will not be able cognitively to perform the steps involved. Clearly, if they can't perform those actions, they also lose some of their ability to feed themselves. Again, modeling is used by the caregivers to get them started. One spouse was complaining that her dementia husband would be drinking his coffee and all of a sudden, just let it "fly" out of his hands. With some observation and questioning, she ultimately decided that he would start watching something outside the window, a bird or a squirrel, and would lose consciousness of the cup of coffee. She made him face away from the window to prevent the broken crockery and the clean-up mess.

The last and most distressing of the ADLs for most people is toileting, which tends to mean that the person needs assistance in the bathroom, needs reminders to use the bathroom, and/or is indeed, incontinent and needs diapering as well as cleaning. Incontinence could be urine, fecal, or both. What can exaggerate the fecal incontinence is that one of the side effects for some of the Alzheimer's medications is loose stools. These spouses who experience this side effect aren't actually incontinent, but just can't get to the bathroom fast enough for the effect of the medication.

The interviews showed dementia spouses before any of these stages, but also showed some at the final stages. The result of the losses related to ADLs puts a big responsibility on the well spouse. Some of them adapt to each stage as it occurs, always thinking that they may not be able to handle the next one, and then going on to master the next one. If the care receiver is much larger in size and weight than the caregiver, all of this becomes overwhelming. If anything pushes the limits of commensal symbiosis, it is probably the last point. When the spouse really stresses over how to do these tasks, there will be a toll on his or her health. There will be falls, for both spouses, and hospitalizations. But there are supports that can help forego the detrimental effects and these will be addressed in the discussion of the last stages of symbiosis.

Besides the physical dependency, which adds to the symbiosis, there is a psychological loss going on as well for both spouses. It is one thing to not be able to remember, or to not be able to carry on conversations, but it is quite another thing to wear a diaper. The visible aspect of this ADL can completely strain what is left of the couple identity. Adult children have to cope with this as well, seeing their parent become incontinent, and knowing they have to wear diapers.

Bella (I-37) provided care for 15 years, but in recent years went to court to become her spouse's guardian, and placed him in a nursing facility. She and her husband have two sons in their late 20's. For half of their lives, these sons have been involved in the care of their father, and have seen him deteriorate mentally. For a recent holiday, one of the sons picked his father up and brought him to his mother's house to celebrate. The nursing home sent a diaper with the son, but no recommendations. As it turns out, the dementia spouse soiled himself during their holiday dinner. The mother and son spent an hour cleaning him in a bathroom, with the spouse unable to really help at all, almost incapacitated by the experience. When the son confronted the nurse at the facility, and asked why they hadn't been told anything, and why his father hadn't worn the diaper when he left the facility for the visit, he was told, "We can't make anyone wear diapers. It's a dignity issue." The son responded, "Dignity? He cried for over two hours. It took us an hour to clean him up."

Normally, with the ADLs, the caregiver usually has a chance to build up to the heavy duty tasks. But even the most capable of caregivers worries that they may not be able to deal with incontinence. Wayne, (I-34) says, "I wonder when the incontinence comes how I'm going to handle it." Unfortunately, some of the day care programs, and other respite services, will not care for incontinent elders. But there are programs that will not only take care of the personal needs, but will even shower the adult and launder his or her clothes. Incontinence does not have to mean institutionalization, although it is a frequent cause.

Louise, I-28, is committed totally to keeping her dementia spouse at home for as long as possible. She is 14 years his junior, and he has only needed a lot of care for two years, but at the time of the interview he was quite dependent. Louise actually took an early retirement in order to be his caregiver. She has had their condo retrofitted so that he can have an accessible bathroom on the main floor. He needed assistance with all of his ADLs including diapering. I asked her how she was able to do all of this, especially since he was about twice her size, and unable to be much help to her when she had to move him. "He's my husband. You do it with love . . . It's not difficult when you love somebody." Because of his dependency on her, she really only had one day each week where she could go out and do things for herself. That was the day he went to an adult day care. Otherwise she was at home with him, 24/7. Her daughter does help, but she doesn't want her daughter to have to change his diaper, so she is reluctant to ask her daughter for help in staying with him. She was hopeful that the new Hoyer lift [a hydraulic patient lifting device to assist with lifting a patient out of bed and into a wheelchair] that the VA was going to install for her would make it easier to get him out of bed. He has fallen previously, and she has been very worried about that.

Another late stage dementia spouse is Martha's husband, diagnosed with a particularly devastating form of early-onset dementia. He can no longer feed himself, so she helps him with that, as she does with all of his other ADL's. She has learned to help him eat soup by using a straw. But his mind is being destroyed by his disease, and there may come a point where he cannot swallow. She dreads that possibility.

So Martha (I-33) can handle what Wayne (I-34) dreads, diapering, but Martha dreads her spouse's potential inability to swallow. There is always a worry for these caregivers. Dan (I-29) is about the same age as Wayne, caring for a similar dementia spouse, and he has already had to master "Depends," a brand of diaper. He describes the task: "If the diapers are just wet that takes two minutes. It's off and on, put some powder in the Depends and it's done."

The interviews suggest that for the majority of the caregivers, it was not the task related to the ADLs that would cause them to give up, to place their spouse in a long term care setting. Rather, it was something else that led to giving up. Matt (I-3) also believes that it will be incontinence that forces him to give up as the daily caregiver for his dementia spouse. But he has handled the other tasks associated with ADLs remarkably well. Certainly, he had the most unique way of dealing with the showering problem, voiced by most of the other caregivers.

> A typical day is we get up. . .I eat breakfast first. I go back into bed, we cuddle a little bit, she gets up and has breakfast. And we always have to take a shower together. . . Even though I can't perform anymore, we still cuddle. She never complains. Some women would say "Leave me alone." I don't care what time of the day, we cuddle up. . . Yeah, if I have to bathe her in the shower, well I bathe her in the shower now, but that is a pleasure.

Thus Matthew continues to provide care to his 85-year-old wife, keeping her clean by using the experience as just one more way that they can cuddle. He almost returns to mutualistic symbiosis, if his wife didn't need so much care. Certainly their showers are mutually beneficial.

6. Care Receiver Stress and Fear

Although care receivers were not interviewed in this study, the narrative from the caregiver pointed out the high level of stress in the care receiver's life. After all, it is the care receiver's brain that is unraveling, and the daily acts we all live by can become monumentally challenging and disabling. But well spouses usually don't understand this cognitive mine field, so they generally just forge ahead, pushing their dementia spouses to do what the impaired partners essentially can't do at that moment.

What will happen to the couple caught in this impasse is that almost without exception, the caregiver takes over and does the task, guides the dementia spouse along the way, and waits for the next roadblock. Samples of these exchanges that further weight the symbiotic enmeshing include kitchen tasks, outdoor tasks, ADLs, etc. For example, when Robert (I-4) takes his wife with him to clean out their sailboat for the season, they have to pack up canned goods, and then when they get home, put them away. He tells her to unpack the bags and put the cans away. When she says she can't, he responds with a clearer directive, "Put them on the shelf." With that, she again says she can't and walks away. Needless to say, exchanges like this add to stress for both spouses, and their marriage is greatly diminished, although the symbiosis is firmly in place. He now steps in and performs the task.

Brenda's (I-8) spouse has been declining for 14 years, but he still watches television. When he sees action shows that include punching etc., he will tell her, "Don't get involved; don't get involved." Often he asks her who else is in the house and she must reassure him that no one is. Many dementia spouses are uncomfortable with grand children and greatgrandchildren visiting, because they do not know who they are, and yet they seem to be everywhere. Some of the spouses actually question any outside guest, because they do not really know who this person is, and it is upsetting to their sense of safety.

While interviewing Kieran (I-36), the 58–year-old spouse of the woman with a devastating form of early dementia, the wife paced, and kept trying to touch the interviewer. She looked outside and worried over the interviewer's car, a strange car parked outside their house. She would constantly return to the interviewer, and again, continue getting in very close, and asking who she was, and why was she there. It was almost impossible to complete this interview.

Karen's (I-2) spouse is still in the early stages of dementia, and knows he is failing. His stress comes from this knowledge. He fears the process that he knows is progressive. But then of course, for the anxious care receivers fear is an everyday occurrence. Fear is what keeps them inside the house; fear is what keeps them from entering an adult day care; fear is what keeps them from saying things to others because they aren't quite sure what the conversation is all about.

A common response from the care receiver is to just go home, just stay home, etc. This is why their sense of isolation increases, and why the symbiosis progresses. Safety is being with the spouse inside the house. Yet it is the spouse that actually can become the source of the threat. Most of the spouses struggle with impatience on a daily basis. Even the most sensitized of the spouses "lose it" from time to time. They feel guilty afterwards, because they know that this is their symbiotic partner, and it is the disease that has created this situation, but their anger gets the best of them, and they react to the care receiver. This is the situation that often produces the most stress for the couple. Bound to each other, increasingly isolated, it is no wonder that these events are the dark side of the symbiosis. The next section, The Tipping Point, takes this progression forward to its logical conclusion.

7. Loss of Intimacy

In most of the interviews, there was a loss of intimacy, both physical and emotional. Although there was no specific question about sexuality, there were questions about feelings, closeness, gestures, which sometimes provoked comments about sexuality. Some of the couples maintained sexual intimacy, but most seemed to think that was over. Robert (I-4) describes his situation as being a bachelor, but still having someone live in his house. Laura (I-10) says she will put her arms around her spouse and he will just stand there, with no response.

Maggie, (I-11) the younger caregiver of her 17-years-older spouse, does speak directly of sexuality: "And I do miss sex, definitely do. I try not to, but it is normal, you know I am normal. It is a hard life right now. And I try to say it is not, but it is." When Sarah (I-12) was asked about when she knew she was the caregiver, she responded: "Truthfully, it was sex . . . there wasn't any anymore . . . and I realized that that life is over."

Not every male caregiver was able to still cuddle with his wife either. Doug (I-18) responded to a question about cuddling in this way: "I get a squeeze and a kiss once in a while. We don't go any further than that. That's been out of the picture for years. That's another thing that (she) kind of like walked away from … if something isn't what she likes to do any more she'll walk away from it. She just cuts it off."

The young caregiver wife, Kathleen, (I-39) also found an end to intimacy with her spouse. His brain damage affected his emotional state. There is very little affect regarding his family. But once Kathleen did try to engage him sexually, and she described it as "horrifying . . . like having sex with a 12-year-old." She never attempted it again.

These were the most striking examples of the loss of intimacy experienced by the caregivers. One might argue that this would diminish the symbiosis between the spouses because they may no longer have the opportunity to replenish the relationship through sex. But that would be mutualistic symbiosis, the type where both spouses would benefit. Now, in the stage of commensalistic symbiosis, the loss of intimacy is just another reason or cause for why the couple's life together is not really mutualistic anymore, but rather one spouse benefiting and surviving because of the other.

Not all intimacy is sexuality, but can be described as closeness. For the most part this also disappeared, though not completely. As Sue (I-32) said, "We used to always cuddle in bed. I was always cold. Now, he's way over there and I'm over here." This distance in bed only serves to point out the loss of intimate closeness, which is quite different than the day-in-and-day-out "physical closeness" due to ADLs and being almost physically conjoined in their symbiosis, owing to the anxiety of the care receiver. For most of the caregivers, this physical closeness is not the intimacy they now miss.

8. Lack of Communication between the Caregiver and Care Receiver

Even for caregiver spouses who did not indicate a major issue with the change in communication, there were always hints about how much this affected them. Most dementia patients do ultimately cease communicating, so the path along the way as the disease progresses, usually is marked by a sharp decline in conversation. Since the amount of time spent together increases, and the time spent with others diminishes, this change in communication between the spouses definitely affects the caregiver.

Amy (I-1) admits she was always the talker in their relationship, but at least she would get a response from him. Now, she says, he just sits there all day and never says anything. Maggie (I-11) still works so she would like to have some conversation with her dementia spouse, but, “you would think I would get that through to my head but I still try to talk to him like a normal person. But then when he repeats a story, I go, “Ok.” And I will read.” Millie (I-13) is often upset by her husband’s mumbling to himself. So she speaks up: “Sometimes when he’s sitting there talking to himself, I say, ‘Don’t talk to yourself when I’m in here, talk with me.’ He says, ‘What I’m going to say?’ I say, ‘Anything you want to say. Don’t make no difference.’ That’ll last a little while and then he goes back with the same thing.” This kind of experience makes her feel lonely, because she realizes “he is a different man now.”

After the interview with Millie, which was spread over two visits, the image of the still house showed up in a memo. The dementia spouses sit in their houses, or walk around, but they do not have anything to do. The well spouses try to engage their care receivers in conversation or activity, but nothing works. Thus, there is always stillness and silence in the house. One knows there is a dementia spouse present, but seldom interacting. There is a ghost-like quality about this presence.

Earl (I-16) is the spouse who has trouble controlling his anger, and really is struggling with caregiving. When asked about communication, he says that his wife will not talk about her frustration as a dementia patient and this is hard for him. “Talk. At least talk.” The same spouse, when asked what he misses the most, says it is communication.

Complicating the communication issue is the loss of hearing experienced by some of the older care receivers. Lena (I-21) really misses being able to communicate with her spouse, because now, not only is he less willing to communicate, but his hearing loss makes every conversation difficult. She has to repeat herself several times, and by then, he thinks she is angry at him. “There’s no conversation. We used to have fantastic conversations.” She describes their environment as “dead air.”

So the care receiver is not engaged, but the caregiver wants to share. That would be mutualistic symbiosis; that is, sharing with each other the events of the day, the new ideas one has felt. But because of this breakdown in communication, the relationship isn’t mutually fulfilling or rewarding. The well spouse is losing one of the big benefits of marriage: someone to talk to and someone who will listen. A few of them pretend, and still share their thoughts, but it is all one-sided, and they know it.

The most dramatic example of the communication loss is the experience of Lawrence (I-14). Lawrence and his wife, a couple in their 80’s, stand out as involved and educated. They both like music, reading, cultural events, trips into Manhattan, subscriptions to theater performances. She had been a public school teacher, but now cannot communicate beyond a few mumbles. While being interviewed, she is curled up asleep in a recliner chair, almost in a fetal position. He spends every day with her like that. “Cognition is virtually nil. I say nil because once in a while when I talk to her she’ll open her eyes and look at me.” He goes on, “It’s very difficult because we’ve been married 55 years and we’ve been very close all this time. Before we were married, we knew each other for 5 or 6 years.” For Lawrence, the really difficult part of the dementia experience is that he and his wife cannot communicate. He sits with her every day, just as during the interview, sometimes reading to her, sometimes playing music for her, but never gets a response. For them, the symbiosis is a quiet embrace.

9. Public Episode

From the first interview, it was clear that caregiver stress was exacerbated by public episodes, times when the dementia spouse shows the true nature of his or her dementia in a public setting. It is usually the public nature of the episode that is so upsetting to the caregiver, rather than the episode itself. This would reflect theories of social identity, especially Goffman's theory of stigma, or "spoiled identity" (1963). According to that theory, people who would be observing the public episode involving a dementia spouse, would immediately see that the spouse differs significantly from other adults in such a situation, and therefore is "less" and weak. In Goffman's words, the dementia spouse becomes a discounted person, someone with stigma.

If this is the case, then how does this affect the caregiver spouse, whose identity is intricately bound by symbiosis to the dementia spouse? Does the stigma spread to cover both of them? Brenda (I-8), caregiver to her spouse for 14 years, has struggled a lot with public episodes because her spouse often becomes physical when he gets frustrated.

> We had a new patio put in, and a path going to the back yard. And the men were working. We had been out. And then we came home, and when he saw them there, he wanted to go that way. And I am saying, "No, no, let's go in the house." I got him in the house. He went to the bathroom, and then I went to the bathroom. While I am in the bathroom, he is out. I am running out after him. And he is going to go that way. And I grab him and say, "No, no, no. Don't go that way. We will go the other…" And he grabs my arm, and I am saying, "You are hurting me." He only had one arm. I am saying, "You are hurting me. You are hurting me. You don't want to hurt me." And he let go. As he let go, he grabbed both of my wrists, and started twisting them. So I let myself down on the ground. I mean he didn't push me down on the ground, or anything like that, but rather than have my arms twisted, I let myself down on the ground. And then naturally he let go. Because I am going down, so he let go.

During this episode, there are two sets of men working, one on their patio, and another set of public employees working on something on the street. No one intervenes. But all were aware of what was happening. This was just one of several times that he has been physical with her, pinning her to a wall, or on the floor or ground. But she handles it by going down on her own, and letting him know that he is hurting her. She does not admit to being seriously hurt by him. Still, we have the question concerning stigma. Does the caregiver share the stigma with the care receiver, because of the symbiosis? If there is really symbiosis, probably yes. This is why, possibly, these public situations are so highly stressful for the caregivers. Barbara's vulnerability around her husband is stressful by itself, but it is really the public nature of it that may bother her the most.

Whenever caregivers told stories about public episodes, they were very specific with the details. Incidents that occurred just between the two of them weren't recalled with the same specificity. Perhaps, it is the stigmatization that burnishes the effect in her mind. When asked if any of her daughters has witnessed this, she replied no at first, but then said yes, and told this vignette.

> Yes, this summer. My one daughter, Deborah. The one that was, she was way in the back yard with her daughter who is 12 years old. I was up here, and I was telling him not to do something, "R, don't do that." And he grabbed me, and she got up, and she said, "You are going to hurt my mother?" And she came running. And my granddaughter, she ran down the other way, she didn't want to see. And she got up here, and he went at her. And I am saying, "It's all right, it's all right, take it easy, take it easy," and stuff like that. She was very, very, "You do that to my mother, my mother!! That's my mother!" She really lost it because she. . .

Brenda has a hard time finishing this story, and really struggles sharing the narrative. These situations arise whenever anyone tries to thwart the care receiver in what he is trying to do. During the interview itself, he appeared holding his belt in his hands. He had taken it out of his pants, and was shaking it, while grinning. It seemed that the presence of the interviewer was threatening to him, and his way of dealing with that was to be somewhat threatening himself. Brenda's daughter was so shaken by the experience that she will not come and stay with her father anymore by herself, but makes sure her husband is along.

This story was not a common one, fortunately, but shows what can happen in the symbiotic couple after fourteen years. His bad behaviors prevent him from being able to attend respite services like adult day care. Brenda is truly trapped, and it has gotten worse in recent months, because she should not drive anymore due to macular degeneration, which she now suffers from. She is trapped within his stigma and even getting together with her friends has become almost impossible. She really can't bring him along so, in effect, she can't go. (This couple is actually in the next stage of symbiosis.)

Many of the public episodes are much more mundane, and often occur around friends, which can work for or against the stigma. Judith (I-9) often traveled with her spouse, to barbershop quartet events, which were a major part of their life. But at some point, he couldn't deal with the experience of staying in a hotel, handling a key, sitting through events, and Judith was supported by his friends, but she knew their days of barbershopping were numbered. Sarah (I-12) realizes her husband is in trouble when he cannot divide up the bill at a restaurant when they are out with friends. Always, he had done this, but on this occasion, he hands the bill to her and says he cannot do it. So she does it.

But then the event can escalate, and Sarah's (I-12) spouse actually was brought home by police officers from his adult day care. There was some kind of argument on the bus, which he takes to the day care. He wanted to get off. Drivers aren't trained how to handle this obsessive dementia behavior, but are told to call the police, so this driver did. And Sarah's spouse ends up coming home in a police car. Sarah was very upset by the police incident, and the obvious stigma involved.

Earl's (I-16) wife has a tendency to wander, which is why he is always locking doors. One episode he recalls that involved a lot of people was when she walked out of the house and he couldn't find her. ". . . had the neighbors looking all over … called the cops and then someone at the bank called me to tell me that she was there. I asked them to hold on to her and sent the cops down there. So they went down and picked her up. It didn't faze her." Doug (I-18) took a cruise with his wife, and she decided to leave the cabin during the night. His heart was pounding when he finally found her, but at the same time, he is reminding himself that the whole thing was pretty funny actually, He sees her, in her pajamas, talking to someone who doesn't understand English, and they are both looking at a map of the ship trying to figure out where she belongs, but both of them are mostly without a clue.

Doug is also the caregiver who has to enlist two other women to find his wife in a restroom, because she wasn't coming out, and they were ready to board their ship. When the two women also failed to return, he actually entered the restroom, only to be yelled at by other women inside. He retreated, and there was his wife with the two women. What he hadn't known all along was that this restroom had two entrances, a situation that would confound the best of the dementia caregivers. But during the interview he can smile about it.

These narratives point out how important social identity is to a couple, and when it sours, there are repercussions. One senses that these caregivers would like to take the observers of the public episode aside and let them know what their husband or wife is really like. Many times they actually did say in the interview, "This is not the person I married." However, the stigma has taken over, and they too are caught in its dark shadow.

10. Situational Stress External Environment

Sometimes the environment itself and what is transpiring in the environment is the cause of stress for both members of the couple. Driving is a perfect example of situational stress. Most of the care receivers have difficulty with driving because they get distracted and accidentally run into something, or because they cannot decide how to react when making a left turn in traffic. Events like this, with the resulting damage to their cars, and perhaps to their bodies, produce significant stress in the caregiver. The theory would be that it isn't just the damage done that is stressful, but perhaps even stronger is the public nature of the event, and what it signifies about the dementia spouse.

Traveling often produced periods of situational stress. Martha (I-23) decided to travel to visit her daughter, and flying made the most sense. Her husband accompanied her, but he was starting to have continency problems so she had him in pull-up diapers. They couldn't find a unisex rest room in the airport before their plane took off, a major issue for caregivers, so they boarded. Unfortunately, her spouse almost immediately had diarrhea, but now they are on the plane.

> We're sitting on the plane and everybody is walking by him saying something smells and I'm going oh dear God and the stewardess comes up to me and she looks at me and I say, "He's incontinent." She says, "Honey, don't worry about it. My husband's a paraplegic. I understand fully. When the plane stops, everybody sits still, I will bring the wheelchair and you will be the first people out." When the plane stopped everybody was told to sit still, "We have to get a sick man off of the plane." They came on with a wheelchair, they got him off. My daughter

> would kill me getting into the car. He was really bad. I found a handicapped bathroom. So now you're trying to take off his pants then there's the rubber pants … what a mess, you need the diapers that look like pampers.

The whole airport and flight experience was stressful for the caregiver, down to the reaction of her daughter if he got in the car all dirty. Fortunately, the flight attendant was one of those helpful strangers or guardian angels written about earlier, sparing her the experience of trying to explain to someone in authority what was wrong with her husband. Unfortunately, most people in service jobs are not so patient and supportive with caregivers. For example, social workers sometimes forget that the spouse who brings her dementia spouse to day care is otherwise at home with him all day long. Bella (I-37) found when she shared with the social worker that she couldn't handle her husband anymore at home, and needed to put him in a facility, she was setting the stage for trouble. "The social worker would tell him I have no right to threaten him with institutionalization. . . . I couldn't place him because his social worker told him to refuse all the time. I had to go to court to be named guardian." Following a situation at home, where her spouse tried to get the lock box where she kept his medications, and they fought over it, he told the social worker that his wife pushed him. The social worker called Adult Protective Services. (Keep in mind that this male care receiver has a serious dementia, and is much larger than his spouse, who is still working full time in order to support her two sons.) "I understand they do have to do it. They came here, two detectives from Suffolk County, Adult Protective Service. I had my lawyer here. By the end of the meeting APS is saying, (he) needs to be in a nursing home."

Sadly, a place of situational stress for many of the couples is the bedroom. During the night, the dementia spouse awakens and for some reason is not clear who the other person, in the bed, is. Their reaction is to tell the "stranger" to leave. Phil (I-40) is visiting his son in Maryland with his dementia spouse and this happens. "She looked at me and said, 'Who are you?' That blew my son's mind." During most of their time there, she kept her distance and wouldn't talk to Phil.

In another case of nighttime mix-up, Amy (I-1) is thrown out of the bedroom, and her husband tries to get her to leave the apartment altogether. "You have to go. I don't . . . you're a nice lady, but you have to get out of here. You can't stay here. You can't come in off the street like that." This dementia spouse with 45 years of marriage thought somehow a strange woman had ended up in his bed, and it offended everything in his being. She would have to leave. It is after midnight. First, she calls the Alzheimer's hotline and they tell her to call the police, but she doesn't want to do that. She does go to another room, and sits in the dark, hoping he won't notice her. But he finds her crying. He sits down on the couch across from her. "You have to have somebody to take care of you. Don't you have any family? Now don't be so upset lady. You are getting all upset."

Next, she calls her daughter who sends her husband over to help, but the trip would take a half hour. When the son-in-law arrives, he finds them at a stand-off. "Pete comes in the front door and he says to him: 'Hey Buzz, what is going on here?' He turns to me on the couch, and says 'I don't know, Amy. Tell him, where did that woman go?'" Amy says it was just like snapping your fingers to draw him out of it. The son-in-law spent the rest of the night on the couch, and they went back into their bedroom. According to Amy, it hasn't happened again, but once was enough.

These episodes of situational stress tend to last for several hours, and thus, are deeply disturbing and draining for the caregiver. In the last example, the situation is perhaps equally draining for the care receiver because he has never had strange women in his bed. How does he get rid of this woman? How did she get in? Why won't she leave? Why won't she stop crying? What a night that must have been for the two of them!

Behaviors of the Caregiver Verifying Commensal Symbiosis

The previous section enumerated ten causes for the commensalistic symbiosis, and those causes, as they intensify, actually become the precipitating factors for the couple ultimately moving out of commensalistic symbiosis, and into the next stage. Before exploring that shift, it is important to ask whether the caregiver realizes he or she is in the commensalistic symbiotic stage? From the interviews, there were certain coded moments that emphasized the well spouse's realization that he or she was responsible for the care receiver, and sometimes must speak for them, or interpret for them. Even those still in the early stages of the dementia knew they had a more active role, and were the stronger member (host) of the pair.

1. Caregiver Behaviors during Medical Interactions

The setting where this was most obvious was when the dementia spouse had medical appointments, testing, or hospitalizations, generally coded for the research as "medical interaction". Moira (I-6) visits her husband in the hospital, and finds that he is not being cared for properly.

> Because I went to the hospital one day, and it was a Sunday morning, and I walked into the room, and the smell would have knocked you sideways. He had, probably the medicine they were giving him, went right through him. And he didn't know enough to change the clothes and everything. I had brought towels and soap and everything with me. And I had a bag, and I said, "Ok, let's go into the bathroom." And I took the clothes off, and a nurse's aide came in, and she said, "What are you doing?" I said, "I am giving him a sponge bath." So she said, "Well, I did that this morning." I said, "I don't think so." I said, "Is it just me, or can you smell what is in this room?" "Oh." And she left me alone.

This scene shows how the well spouse does much more than visit her husband in the hospital. She plans ahead, brings supplies for bathing with her, asserts herself and does what family members usually do not do while the elder person is hospitalized. When questioned by the personal care aide, she just states her case. He smells bad, and I am cleaning him. The symbiotic attachment is not only acknowledged but accepted and acted upon. She comes prepared to clean him. He cannot do these things for himself, so she will do them.

This caregiving is what symbiosis expects, and in commensal symbiosis, there is a stronger spouse, providing for the weaker one. That is the scenario in most of the interviews. Certainly, Moira is a calmer, more efficient caregiver. She doesn't complain about her husband's care; she quietly provides the care herself. Even her daughters tell her caregiving is easy for her because she has provided care to others during her life. When the interviewer suggests that, still it is different doing this for your own husband, she says: "It is. It is. It . . . but again, you look at them, and you say, 'Oh God.' You know. There but for the grace of god . . . And somebody has got to do it, and I would prefer that it would be me."

Rita (I-5) begins to accompany her husband to the doctors when she feels they are not getting their questions answered. She knows there are medications that he could start taking, but has held off. Her husband doesn't want to take them, and she doesn't know if he is ready yet to make the risk worthwhile. At some point, the doctor urges the medication and she agrees. The husband balks. "Of course B. says, 'I am not going to.' And I said, 'It is not even up for discussion.' I said, 'I am your caregiver . . .'" Again, the spouse intervenes to make sure that the dementia spouse gets the medication he needs. She asserts herself as the stronger partner at this point, the host, and coerces the weaker partner, her husband, to start the medication. Since it is common for dementia patients to be obstinate and oppositional, her tactic averts endless arguments and illustrates the imbalance in their commensalistic symbiotic relationship.

2. Caregiver Problem Solving Skills

Further self-validating behaviors by the well spouse signifying his or her role as host partner are the extensive use of problem solving skills. Mutualistic symbiotic partners do not have to routinely create methods of handling their spouses that will avoid physical confrontations, crying, wandering, withdrawing, etc. Commensalistic symbiotic caregivers have to be creative problem solvers every day. Amy (I-1) knows that her spouse will just shake her off if she reaches for his arm while they are walking. However, if she says: "Gee, my legs feel very weary today, do you mind if I hold on to you?" he is willing for the personal touch. Several of the caregivers use music and dancing to help improve the mood of their dementia spouses. Because dementia spouses have a big craving for sweets, caregivers make sure they are using *Sweet and Low,* rather than argue about the amount of sugar in coffee or tea.

Most of the problem solving requires distracting the spouse, or sometimes lying to the spouse in order to divert them from what it is that they are obsessing about. Some of them use the "police" as part of the rationale why the spouse should or should not do something. Sometimes, the rationale or lie is that the caregiver will give up and the dementia spouse will have to go to a nursing home, or back to his first wife, or something equally nasty. All of this subterfuge again signifies that the well spouse is clearly aware of his or her host role, to protect the other partner, to help the other partner.

3. Caregiver Strategies to Protect Image of Dementia Spouse

Caregivers also show their recognition of their dominant role in the relationship by the way they protect the image of their spouse. This has been addressed previously, but here it is being used as more evidence of their acceptance of the commensalistic symbiosis. When Amy (I-1) senses her husband’s limitations in a public setting with friends present, she says, “We used to go out to dinner a lot. I don’t do that really anymore. You know. Being with friends. When you are with friends. I have been blessed with good friends and even when we are together with couples we have spent our lifetime knowing, to look at them, and to see where we are at, is hard.” Here Amy is saying, it is more than protecting my spouse’s dignity. It is protecting our dignity, the symbiotic couple.

Outcomes of the Commensalistic Symbiosis

In the commensal stage of symbiosis, the caregiver faces some practical concerns, topics that showed up in the interviews rather frequently. These practical concerns are the result of the new relationship between spouses, an uneven relationship, where the dementia spouse is giving up most roles associated with being a husband or wife. This then shifts the role(s) by necessity to the well spouse.

1. The Role of Mastering Home Chores

The imbalance resulting from the weakening of the dementia spouse, means that home chores take on a huge role in the everyday life of the caregiver. These are not assisting with ADLs, but rather that whole range of tasks previously shared by the spouses. These chores are what have to be done in addition to what the spouse previously did, as well as the increasing physical care of the dementia spouse. And these are the tasks that really do lead to the "tipping point" in the number of stresses a caregiver can adequately handle. Some of the most able and competent caregivers admitted getting completely stressed out by some unexpected household task.

These household tasks vary, but Lucille (I-35) discovered early in her caregiving career, "that I can't stand if I have something that needs to be done. I have to do it." Where before she probably would have nagged her husband to do it, now she knew she had to find someone else. In her case, to lighten the stress, she hired a handyman. But Lena, (I-21) tried to do these chores herself as long as she could. This took away from her personal time, and made her more resentful. Eddie (I-22) is completely overwhelmed by cleaning his apartment. "It's very hard for me to cope with all this. It's all new to me. I have to do cooking and cleaning and washing clothes and ironing clothes. The drapes have to be washed and ironed. I don't have time for myself. I have to do something here every day of the week." Add to the pressure of the tasks, the fact that these are not young caregivers. Lena is only 75, but Lucille is 82 and Eddie is 85. They are exhausted.

2. Caregiver Worries about Money

Another big outcome of the commensalistic period is that the caregiver worries more. First, the well spouse worries about money. They see that this dependence is a downward trajectory, and they know there are expenses ahead that put a strain on them. Part of the arsenal of defenses against the strain on the caregiver, are the support services. However, these require out-of-pocket expenditures by the caregiver, and until the care receiver qualifies for Medicaid, may be too high for the caregiver to absorb. Thus, the financial strain takes hold.

Matthew (I-3) at 82 has done some financial planning, but asks questions about adult day care, which is probably a good option for his wife. Whether he can afford it or not, he doesn't think he can. He has heard that it can cost $150 per day, and he doesn't have any long term care insurance or Medicaid coverage. "Looking at these guys that have their wives in Assisted Living. I don't know how they do it."

Because these symbiotic couples need some change in their day, many choose to go out to dinner frequently at fast food restaurants mostly. This is the one bright spot in Brenda's (I-8) day. "I am running out of money, but that is beside the point." If she can't do the restaurant, she takes her dementia spouse to the mall to walk around. He cannot go to adult day care, because of his behaviors. Laura (I-10) desperately would like to have her spouse go to a social model day care one more day each week, but the extra money would have to come from her step-daughter, and she just gave Laura money for a cleaning service. So Laura is torn, and angry. She blames her dementia spouse for bad financial decision-making in the years leading up to his diagnosis, and she didn't have these worries previously in her life, when he was a good provider. Blaming the care receiver was not common in the interviews, however.

Kay (I-19) is one of the younger caregivers and she shows great stress when she shares these thoughts about her financial situation. "Money is really an issue … a big issue … probably I should have moved when I first realized this was happening. I did have the presence of mind to go to the lawyer and we have the house now in a trust and stuff and I have a financial guy which I really didn't want to have at all but I can't keep on top things at all and I had so little I didn't know what to do with it."

But her situation is not quite as bad as Martha's (I-33) because her husband has a pension and she still owns valuable property, her house. Martha's husband, again in the years running up to the diagnosis (ten years), almost bankrupted the family, which in those years included a college-age son. He put all of the bills they received in the trunk of his car and kept it locked. When LILCO let them know that they were going to turn off the electricity due to nonpayment of bills, a fight ensued between the husband and her young adult son, his stepson. The spouse would not open the trunk of the car. When they finally got it open, it had 5-6 months of bills inside. She emphasizes how destructive the financial piece was to both of them, and how long it took for her to get back on her feet. ". . . he really did destroy us … he filed his taxes for 5 years in the basement. I'd say, 'You file your taxes?' 'Yep.' The IRS was at our door, they were going to garnish my salary."

3. Caregiver Worry about the Future

A related worry that many of the caregivers speak about, resulting from their experience in the commensal stage, is worry about the future. One of the questions in the guided interview concerned their thoughts about the future. Obviously, many of them were worried about the placement of the spouse in a nursing facility, or having them go into an assisted living. But the worry that pointed out the dangerous direction their symbiotic relationship was headed, was their worry about their own health, and what if something happened to them, and who would take care of their spouse? This is the verification of the commensal symbiosis, but it is also the result of the commensal symbiosis. A caregiver who worries about his or her own health and safety, not in a personal way, but rather because of the effect it will have on their weaker partner, is definitely locked up tight in the symbiosis.

Elizabeth (I-7) is definitely worried. She has been having neck pain, so she now is asking herself, what is this? “My biggest worry is not me, but if I have to go into the hospital, he can’t be here alone. You know, they keep saying to me at the Club (support group). You have to have a plan. Where, what plan can I have? I have nobody to call even.” She believes that her son’s plan would be to put her spouse in Assisted Living, but that plan isn’t all right with her. She wants a different plan. “I want the plan where I can keep him here as long as I can keep him here. Because he doesn’t belong in Assisted Living. I say to myself, which is why I want to go to speak to somebody, that maybe I am going to have to live in an Assisted Living with him. Because you can do that. Even though I don’t want to be there . . .” For Elizabeth, the symbiosis is more important than her own independent living.

Amy (I-1) develops breast cancer during her husband’s illness, and worries that she won’t be able to care for him due to her chemotherapy. In her words, “That is why this whole chemo was such a big decision thing for me, because I thought am I still going to be able to take care of him, and go through this (chemo), and God has been good.”

Sarah (I-12) is worried about her own health, because she would have to leave him. “I had where I had to go for a biopsy and they wanted me to stay overnight and I couldn’t stay overnight. I had no place to leave him. Unless one of the kids came and stayed here. If it was absolutely necessary maybe they would do that. He wouldn't like it. He probably would wonder why they're here. That is my biggest worry. What's going to happen."

The male caregivers also worry if something happens to them first. Doug (I-18), like several other caregivers, likes to have everything under control. "The future is pretty much … I've just got to live through it. I don't know … the one thing I don't have *covered* is if something happens to me." None of the caregivers like the thought of leaving this responsibility to their adult children. However, the majority of male caregivers were more accepting of the reality of nursing home placement. They were trying to do whatever they could to care for their spouses at home, but were more open generally to nursing home placement. More of the women were not.

Betty (I-23) knows that her sons will help her out if she needs help, after her husband dies. But if something happens to her . . . "That's something that I'm praying never happens while he's like he is." She doesn't believe he would survive a move to a nursing home. Kitty (I-26) says essentially the same thing. "Because I pray that we should go together. I do worry about I don't want to go before him because I know they'll put him in a nursing home. They have their own little lives. I don't want him in that. It's good for some people. They neglect the elderly. They don't care. I really think a lot of them don't care. If we go … I don't want to leave him."

Tipping Point: Caregiver Endangered by Symbiosis.

Each of the preceding topics of Stage 4 Commensalistic Symbiosis points out the level of danger in these symbiotic caregiving relationships. One can hear in the voices of the caregivers a dawning realization that they are starting to weaken as well. Sometimes it is physical as in cancer, arthritis, osteoporosis, hypertension, pulmonary problems, loss of strength. Other times it is the fraying edge of their mental state. Either way, commensalistic symbiosis is ending, and they are approaching what seemed to be an actual tipping point, a precipitous loss of balance, that will send the caregiver into a personal maelstrom.

Being in a symbiotic relationship with someone who is weakening, sometimes in very frightening ways, tends to ultimately affect the stability and strength of the well spouse, no matter how much they try to withstand that effect. What happens at the Tipping Point is that there is some build up of pressure or stress that pushes the well spouse in most cases to clearly lose ground as the host member of the symbiosis. Eleven axial codes appeared to press the trajectory toward the tipping point, or the fifth stage of symbiosis. All of these precipitating factors began with little stress for the caregiver, but gradually strengthened, increased, deepened, etc. so that the caregiver feels threatened by them, hurt by them, and ultimately, depressed by them. Seven of these codes were already addressed in Stage 4, because they began at a more manageable level, but increased in intensity as the disease progressed. These seven are:

1. **Lack of Communication for Couple due to Dementia**
2. **Stressful Medical Interactions**
3. **Care Receiver Dependency**
4. **Assistance with ADLs**
5. **Situational Stress of External Environment**
6. **Care Receiver Health**
7. **Loss of Intimacy**

The remaining four axial codes leading to the Tipping Point include:

8. **Caregiver Stress**
9. **Caregiver Need to be Alone**
10. **Caregiver Anger**
11. **Caregiver Health**

Caregiver Stress, #8, includes and repeats many of the other codes, but needed to be listed here, because it was coded most frequently in the interviews. It was jointly coded most of the time with another more specific factor. The remaining three will be addressed here: Caregiver Need to be Alone, Caregiver Anger, and Caregiver Health.

During the interviews, one of the questions concerned the greatest challenge facing the caregiver. Nine of the 40 caregivers indicated that the greatest challenge for them was their need to be alone**,** to get away, to have time for themselves. Four more indicated that isolation was the greatest challenge to them. Although being alone and isolation would seem to be the same condition, they were voicing the same need in two different ways. The need to be alone represented their need to be unto themselves, not with their spouses. The isolation challenge meant being cut off from others, but still with their spouses. It was the actual attachment to the dementia spouse, the endless presence of the dementia spouse that was their greatest challenge, or in other words, the symbiosis itself. This was the largest category of responses and deserves attention at this point.

The first hint that needing time to be alone was a great desire on the part of the caregiver came when they reported on how they spent a typical day. Many indicated that they treasured their early morning hours or late night hours, and either woke early or went to bed late in order to have time for themselves. Because spousal caregiving is 24/7, these private moments are safeguarded. Other indications were those caregivers who pursued an art form at home, or who practiced a craft. In more than one case, this work had to be put on hold, because they didn’t have an opportunity to work by themselves. As soon as they would start, the care receiver would come in and need something, or start handling the materials to the detriment of the caregiver’s pursuits.

One woman, who is a recognized artist, hasn’t created anything in the three years that her spouse has retreated within. Their social life has almost stopped altogether, and except for her college teaching, she was within the home with the care receiver, going nowhere, and creating nothing. She would like to visit her children out west, but doesn’t have a plan for how her dementia spouse would be cared for. It is hard to know which of these losses--her art, her family, or her social life is most difficult for her, but it is clear in talking to her that she needs time for herself. The symbiosis has crossed over into the realm of toxicity, and unless she can find a way to make time for herself, there will be a serious physical or mental toll on her. She has given up so much about her own identity to be in this symbiotic embrace.

Several caregivers are nearing this tipping point. Currently, they can still leave their dementia spouses at home, sometimes by themselves, and they go out to pursue what makes them happy. One likes to play golf and generally be outdoors; another likes to be in a women's prayer group. But they know these days are numbered. Doug (I-18), a caregiver for more than ten years already, says: "If I couldn't get away, I don't know what I'd do." The significance of 13 of the caregivers responding that essentially, it is the symbiosis itself that challenges them, points out the dark path that the relationship is taking, and thus, the impending toxicity.

The word "toxic" begins to surface at the tipping point, since the notion of tipping, losing balance, implies a shift to something dangerous for the caregiver. From the biological meaning of symbiosis, toxic would describe what happens when the relationship becomes parasitical, where the host has to weaken in order for the other organism to survive. However, in this marital context, the use of parasitical is inappropriate. What was once vital and productive about the mutually symbiotic couple, has grown into something dangerous, and for the purposes of the metaphor with symbiosis, toxic. Chapter 5 will develop this concept in greater detail.

In addition to the expressed need to be alone, to have time for personal pursuits, another factor pushing the caregiver to the tipping point is his or her own anger. Usually this anger occurs among caregivers who themselves suffered from some kind of mental illness. For example, Laura (I-10), the 73-year-old caregiver who felt stuck in suburbia, was being treated for depression. She coded three times more for anger than anyone else. The male caregiver who coded a little higher for anger, indeed also suffered from post traumatic stress disorder from a wartime experience.

Anger is very upsetting to the care receivers and makes them fearful. However, it is the end result of the impatience described by most of the caregivers and is definitely a potential emotion that is hard to control. At its most serious level, it can turn into abuse, a clear sign of having passed the tipping point.

The last of the indicators for the tipping point would be caregiver health. As the dementia spouse gets weaker, so too does the caregiver when the tipping point is at hand.

The cancer returns; the chronic condition worsens; the caregiver falls or has to be hospitalized. These are signs that the caregiving and symbiosis has taken a toll, and there have to be some changes. Another warning is lack of sleep. There is usually so much stress that there are somatic changes.

Phil (I-40), a 70-year-old caregiver for his spouse, has been supportive of her from the early days of the change. They are very close to the tipping point in the symbiotic relationship. He has been caring for her for six years. In the early days of her change, he actually learned how to do her job so that he could help her with her business. She was making errors and he wanted to rescue her and the business. They did everything they could to identify the disease and then to slow it down, but at this point, she has lost ground. While she still knew what was happening, she started a journal and put in the journal her thoughts, many of which showed her anger toward Phil, clearly a projection of her feelings about the disease. But she didn't share these feelings with him. When they were supposed to go to Aruba, she wrote him a letter, saying she was sorry, he should go without her, she doesn't deserve him, etc. But again, never said these things to him. He says she should have said them to him.

She now goes to an adult day care and he is trying to fit into a support group for himself. What is most troubling to Phil, at the point of the interview, is that he knows he is losing her. She is going into the stage of sleeping. No longer does she stick to him like glue. Her dependency has increased, but her time at home is mostly spent sleeping. He is desperate for human contact and conversation. He wants to discuss their plans for possibly moving to live near their adult son. What makes this so exquisitely sad is that they spent most of their marriage advocating for their deaf son. They were a real team. When the dementia began, they shifted into the gear of advocacy again, and tried to find her the very best science, the very best medicine. Even so . . . the progression is the same as for the others. She is physically, symbiotically dependent on him, and there is no hope of returning to soul-mate status. This is how he describes his current mood, which worries him.

> My mood also because I find myself … not depressed but I'm really dark. This is something that's not new. Whenever I come to work … I was always in a position where I had people under me and they knew to

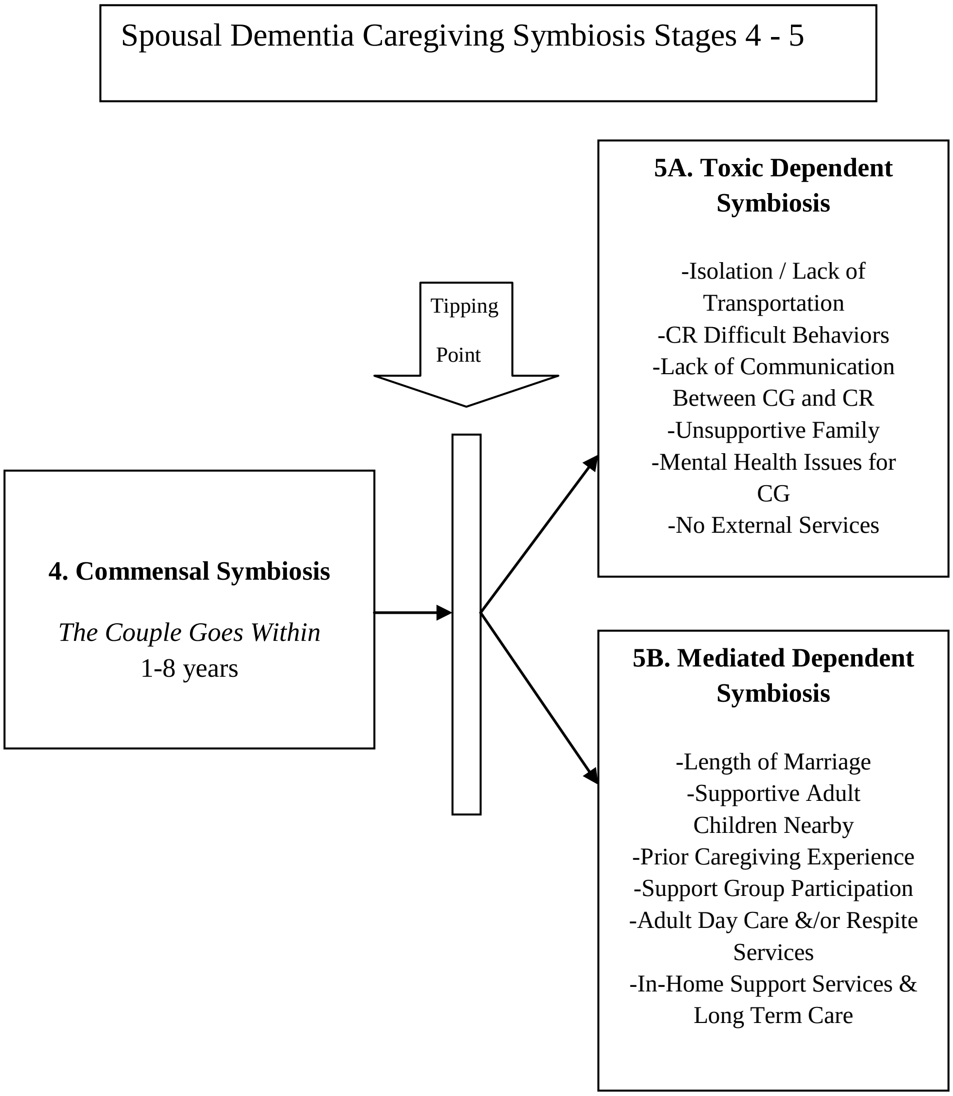
> keep away until a certain part of the day … Phil's in a lousy mood. I'm moody and introspective … come to me at 11 A.M. … don't bother me until I've had a couple of cups of coffee. It's nothing new but I find myself drifting into oh jeeze, what's life about … not a depressing thing, I just don't want to be bothered … leave me alone. I don't say it but I've thought it. I'm internalizing.

Phil needs to make a change, and to do it soon. His story points out so many of the hallmarks of the earlier commensal stage, as covered in this chapter. His wife loses mastery of her vocational roles, so Phil jumps in and tries to learn her job, in order to cover for her. She starts a journal about her feelings toward the disease, but cannot share her feelings verbally with Phil. Loss of communication is a major threat to Phil's coping ability. They had earlier been a strong team, advocating for a disabled son, but now they are almost living in separate worlds, and yet still in the same room, the same small house. He as much as admits a tendency toward depression, something he has accommodated throughout his life, perhaps buoyed up by his wife and children. But now he is alone, knowing he needs human contact and conversation, but not sure how to go about getting it. He worries; he mourns; he is surrounded by the detritus of his past life with his spouse, his soulmate, and overwhelmed by all of it. This is a caregiver who has passed through Stage 4, being the strong one, so that his wife could adjust to her illness. Now he knows that he is on the edge, with no one to hold him up. He is at his tipping point. Thus, this chapter ends, and Stage 5 begins.

CHAPTER V: STAGES 5A AND 5B OF THE SYMBIOTIC STAGE THEORY

Up to now, the design for the stages of symbiotic spousal caregiving has shown couples caught up in a relationship which is still very meaningful to them, but steadily changing, as it moves from a mutual interdependence to a commensal dependence, where one member of the couple, the well "host" in the relationship, now must stay strong in order for the dementia member to survive. But as was shown in the previous chapter, the disease is progressive, and with each new responsibility, the caregiver faces challenges. There comes a time in the commensal relationship where the host realizes that there is damage being done. Both members of the relationship are diminishing. The stage theory suggests that at some point, the tipping point, the well spouse, or the family, realizes that the relationship can't go on the way it is. Toxicity is setting in.

In the biological sense, this would be called parasitical symbiosis, a dependent relationship between two organisms, where the weaker organism will live off the host, ultimately leading to the weakening of the host, and perhaps to its death. However, the word parasitical is not appropriate for describing the dementia care receiver. It is their disease that has made them so dependent, and they have a wonderful rich identity pre-dementia which must be respected and honored. Thus, the term **toxic** seems more appropriate, for it is a very dangerous stage for the couple, it is life-threatening, and it needs to be addressed. Out of forty caregivers, 10 were in the toxic stage, where their well being was on the line. Yet in most cases, that toxicity could be mediated into a healthier state, called Stage 5-B in this research, that is, Mediated Dependent Symbiosis. It is this split in Stage 5, allowing for two options, that makes this stage theory unique in the caregiving research. There were clear differences in how caregivers further along the caregiving trajectory handled the threats to their own well-being. Some retreated, brooded, and were generally unsupported while others reached out for family, support, and services. This marks the difference between a "toxic" dependent symbiosis for the caregiver, and a “mediated” dependent symbiosis. This chapter of the stage theory will look at what marks the toxicity, and what marks the mediated experience. Below is a graphic representation of Stage 4, Tipping Point, and Stages 5A and 5B. The complete drawing is shown in Appendix 5.


Spousal Dementia Caregiving Symbiosis Stages 4 - 5

When the care receiver is so dependent that it is endangering the welfare of the well spouse, the symbiosis will either be toxic or mediated, but either way it is dependent symbiosis. Whether or not the care receiver enters a nursing home doesn’t change much about the symbiosis, but it can relieve the toxicity. However, there are many other mediating factors, as will be seen in the second part of this chapter. But first, what does the toxic symbiosis look like, what are the factors creating it, and how does it affect the caregiver?

Stage 5-A: Toxic Dependent Symbiosis

Toxic dependent symbiosis looks like a relationship that has gone out of control. The caregiver usually is distracted, tends to have negative things to say, cannot find anything positive in the experience, is experiencing personal health problems (both physical and mental), and seems very unsure about decision-making. Not only is the toxicity detracting from the caregiver's health, it is permeating the couple's day-to-day life, and there is a certain desperate and indefinite quality about the situation. To clarify, the toxicity is not the dementia, which of course is progressing, and adding more challenge to the caregiver. Rather, it is the cumulative effect of the stress on the caregiver, as well as the absence of outside support and services. The caregiver is shouldering too large a burden, mostly alone.

An example of a toxic dependent symbiotic couple is Maggie (I-11) and her spouse. They are the couple that has the 17 year difference in their ages. They had met each other through Irish dancing and culture experiences, and enjoyed 8 years of dating, and a deepening relationship. Both had families from prior marriages. Maggie was still employed, but John was retired. Finally, they decided to marry, and that is when his decline into dementia seriously began. Now she realizes that he may have been developing dementia up to eight years earlier, but she wasn't paying attention. (See Stage 2: Pre-diagnosis.) At the time of their marriage, he was also going through prostate surgery, so that there actually were significant changes from their wedding day forward. He became incontinent, and impotent and the cognitive decline worsened.

During the interview, Maggie shared more and more of her frustration. She needed to go to work, but his incontinency and inactivity were a concern to her. He had stopped driving, thankfully, but he wasn't really getting any stimulation when she was at work. Furthermore, she worried about whether she should be leaving him alone or not. She had not yet found an Adult Day Care that was convenient and appropriate for him. Almost everything about their romantic days has been taken---his ballroom dancing skill, his conversational charm, his handsome dressing style, and his gallantry. She wants him to be able to get services, but she is the one with the money. He is not as financially secure. Not only does she own the condo they live in, but she also owns her own business. She is intelligent enough to know that her assets might have to go for his care, and this worries her. He really needs to be on Medicaid ultimately, but she hasn't done the planning yet.

Her children are supportive, but his children only moderately so. One daughter seems dysfunctional herself, and the other has several children, and not too much ability to cope with incontinence. During the interview, Maggie's stress starts to pour forth. He is not present, because he is staying at his daughter's. She reveals how much she misses his former identity, and goes on to say, "And I do miss sex, definitely do. I try not to, but it is normal, you know I am normal. It is a hard life right now. And I try to say it is not, but it is." She tries to find something good, but can't.

> It is hard to be closer, because of his frustration and his bickering and yelling. Which is just the frustration, I know, it is not me. . . But it is, we are slowly growing apart, to a point. But you asked me about conversations. He can't really follow with other people, with the group. But even just the two of us, if I come home, at night, after working, he will say, 'How was your day?'. . . I mean I can't give him problems, I can't say, 'oh, the pipe burst, or the oil spilled.' He'll go, 'Oh god.' But he has no answer. He can't think.

When asked if she had changed, she said, "Slightly. Just lately I have noticed it. I am overwhelmed. I am not . . . helping my daughter as much as I used to. My mind is single minded now on him." She goes on to say even more, "I admit that I am tired. And I am overworked. I have been sick, you know, so now, I can't physically do my job in the day, and come home and do this job then."

At the end of the interview, I ask her if the dependency of their three years of marriage bothers her, and she responds, "Oh sure, I want to be taken care of. And I did. And I was. But not now." Maggie is either just at her tipping point or is in a toxic dependency symbiosis. She does not have much support from his children; she must help him with ADLs, especially incontinence; she has to deal with his difficult behaviors and although he is never abusive, he is very angry and shows it by yelling; she has to balance her job with the caregiving; she has to figure out the financial planning so that she is protected; she cannot find appropriate services for him; her health isn't good; and her home is not a safe haven for her.

What keeps her going at this point are her own supportive children, her faith, her sense of humor; and her love for this man which has survived all the indignities and changes. But these supports may not be enough to save her. She needs more support by way of services. She is living in a toxic dependent symbiosis.

Maggie's case is the introduction to toxicity. What follows here are the six factors that were associated with toxicity in the interviews. They tended to show up significantly in the interviews of those caregivers showing extreme stress.

Factors Contributing to Toxicity

1. Isolation and Lack of Transportation

Eddie (I-22), the 85-year-old caregiver for his dementia spouse, is in the stage of toxic dependent symbiosis, and most of it is due to the fact that he destroyed his car in an accident, and since then has lost his sense of equilibrium. It is hard for him to talk or think about anything other than how he can get another car. He lives in a senior complex, and his spouse gets a number of senior services. She is transported daily to adult day care, and has a home care aide to help with showering twice a week. The showering assistance is because she has difficult behaviors, especially in the shower. Twice a week may not be enough because she is incontinent. Although she gets out to her day care, Eddie is trapped without a car, and the apartment is small. There doesn't appear to be communication anymore between the spouses.

Besides fixating on the accident and his lack of transportation, he also fixates on cleaning the house, and cooking. This is his world, and he appears to be suffering from depression. Two different agencies are visiting him, and trying to work with him, because they fear suicide. He mentions suicide during the interview, in response to a question about designing a service that currently doesn't exist. He says, "Commit suicide. I was so down and so beat up I felt like saying oh forget it Eddie. I came home and M. (daughter) called me on the phone and I started talking to her and I was all right.

It happens. I think about doing it because I get so down and so fed up with everything and I really can. It's a shame but … that's the way it is." Earlier he had referred to himself as "Rotten Eddie." When asked what he means by that response, he doesn't answer. It is a very dark response. His overall distracted behavior during the interview, suggested the toxicity as well.

He does have a daughter nearby, their only child, but between her mother and father, she has her hands full, not to mention her own life and family. There is a sense that Eddie needs more than any array of services could provide. He actually was getting more services for himself and for his wife than most of the couples.

This couple is a perfect example of how the equilibrium can take a nose dive in the caregiving relationship because one variable changes, previously described as a tipping point. In this case, the variable is access to a car, driving. When Eddie has a significant auto accident, totaling his car, he goes from generally coping day-to-day, to a significant mental drop in stability. For this reason he now has two case managers from two different agencies. A local church also sends a male volunteer to take him shopping. Everyone is concerned about his state of mind.

2. Difficult Behaviors of Care Receiver

This topic was covered in several ways earlier in this chapter, but at this point, the difficult behaviors have pushed the couple into the toxic dependent symbiotic stage. Brenda (I-8) has been providing care and support capably for ten years, because her husband was struck very young, with deafness, and then cognitive loss. He is frustrated with his situation, but he is only 77 and still strong. This leads him to be physically disruptive, often focusing his anger on her, and pinning her to the wall, or the ground. This would all be bad enough, but she is the most trapped of the caregivers so far, since he cannot go out for services, because of his behaviors. Day care won't work for him. Her fears of his reactions keep her trapped in the house as his caregiver. She isn't even comfortable turning the responsibility over to her family.

Part of this is just fear of the consequences, but this image of her husband as a brute is so appalling to her that she must prevent it at any cost. There is no easy solution to this, unless a medication could tone his behaviors down. He can be menacing, as can be seen during the interview when he was swishing his leather belt around, and saying it is for using on bad children. He feared a stranger's presence, she said, so his anxiety was leading him to announce his presence and his power.

Furthermore, she is isolated, because she is developing macular degeneration, and is very worried about driving. She has always taken him out, to help them both break free, but even that is threatened now because of her vision. Will she be able to give him up? That is hard to say. She is thinking about nursing home placement, which is her only way out at this point. Still, the symbiosis goes deep. When he gets down, frustrated by his situation, she rubs his back and says, "Then I will tell him I love him. And I love who he was. I don't know if I love him the way he is now. But I love who he was."

3. Lack of Communication between Caregiver and Care Receiver

Most of the couples in Stage 5A or 5B do not have much conversation. All of the dementias eventually take away from the verbal ability of the dementia spouse, many of whom also have hearing loss. Even non-verbal communication is rare. Robert (I-4) is an appropriate example, because much of his distress was caused by the fact that his spouse no longer spoke to him, but instead spent most of her time in his presence, crying. This interview was very painful, because from the beginning there was an absence of humor, little positive feeling about the experience, and almost no confidence from him about being able to handle the experience. Clearly, more than most, this caregiver was using all the information at his disposal and always seeking more, to help him care for his wife. However, her deterioration was so intense, so fast, that his loss was almost unbearable. He didn't share any details about intimacy or affection. Her identity had completely changed for him from a spouse to a crying victim of a horrible disease. Because there wasn't any communication between them anymore, his identity as a spouse was gone. He had supportive family, attended a support group, could afford supportive services, had long-term-care insurance, and good friends who were accepting. Yet, his loneliness in his own home was palpable. He was trapped. He didn't see any way out. This is not usual for him, because he clearly is a strong, in-charge kind of guy.

He and his spouse are relatively young, 65 and 64, and it has been just two years since diagnosis. Her dementia seemed to be progressing more rapidly than others. When I asked him how he responds to the crying, he says, “Now I just laugh at it. But not all the time. It is. . . Even just talking about it now . . . ” At this point he couldn’t say anything; he choked up. When asked for the most challenging part, he immediately says it is “no talking.” He can’t think of anything he does for her that makes him feel good. He is overwhelmed by his feelings of impatience and anger and frustration. Although they had had some arguments over the years, it was nothing like his feelings now. He sometimes just has to walk away. Although we discuss the service options, he isn’t comfortable with any of them. This is part of this toxic stage. The caregiver feels the bonds, feels tied to the care receiver, but doesn’t see any solutions. This isn’t because there aren’t any options, but because he can’t make decisions; he sees walls everywhere, and no doors.

4. Unsupportive Family Members

This is another factor discussed in other sections, but here the lack of support contributes to the toxicity of the situation for the couple. In this respect, there weren’t really very many cases where adult children of the caregiver were completely unsupportive. However, children at a distance weren’t usually helpful, and step-children weren’t very supportive. In the toxic cases, Laura (I-10) stands out as portraying her children as not very supportive and definitely contributing to the toxicity. They are her step-children also, but she raised them. She married a widower with two children, and they called her mommy.

At the time of the diagnosis, the children did not believe her when she said he was doing odd things. She called them, his “peculiarities.” She believes that both of her children are so involved in their own lives, that they do not want their parents to bother them. Both appear to be affluent. On the other hand, the dementia spouse lost most of the money that he and Laura had. Finances are one of her worries, and she has to go to the adult daughter and beg for money. In addition, the house has been signed over to the daughter, for planning purposes. Regarding her son, “Before I got the official diagnosis, I told both my children, individually. I told B. . . 'I want you to help me.' And I told my son. And my son, said, 'Don't look for me. Don't look for any help from me.' He said, 'I'm out.'"

Later in the interview, Laura becomes openly emotional and cries and says, "I don't know what to do. I don't know who to talk to. I don't know what to do. (She is openly crying now.) When I talk to my daughter and son, they don't want to hear about it. It is very hard. Oh, I am not saying they aren't nice children." This actually shows one of the problems understanding Laura. It also signals once again the toxicity of the situation. She wavers back and forth about her feelings for her children, and also for her spouse. Just after saying something negative and spiteful about one of them, she softens it with, "Oh, I am not saying they aren't nice children."

Whether or not her adult children recognize Laura's tenuous situation isn't clear, but Laura does not believe they do. "I'm frightened. I'm frightened. I don't know what. . . B. (the daughter) says we'll handle it when it happens. It is happening though and they can't see it." Clearly, Laura's mental status is unstable, and her adult children have somewhat turned their backs on their parents. The symbiotic situation at this point is toxic and dangerous for both spouses.

5. Mental Health Issues for the Caregiver

Several of the caregivers in the toxic dependent symbiotic stage are experiencing mental health issues of their own. As seen in the examples above, the mental health of the caregiver at Stage 5 is fragile to say the least. Sometimes, this is a reaction to the dementia experience, and sometimes it is symptomatic of a lifelong problem. Laura's issues appear to be part of a lifelong pattern, intensified by the stress of the symbiosis.

Another spouse with a degree of mental illness is Earl (I-16), the 76-year-old caregiver of his spouse of 50 years. He suffers from Post Traumatic Stress Disorder (PTSD), related to Korean War experiences. He speaks openly of his trauma and how it is coming back to him. ". . . when I was overseas in Korea, fighting the war. I think I was angry and also scared. The experience that I'd gotten from the war doesn't help me because they seem to come to the surface when you get older and you have more time on your hands. Like PTSD. But if I went through that, I think I can go through anything." He views his experiences as negative because they come to the surface and upset him, but he also views them as the standard against which he can judge his ability to withstand challenge. If he survived his war experiences, he can survive anything.

Earl is the only Asian subject, who fought in the Korean War for the Americans which is a large part of his identity. Although in their seventies, he and his wife both look quite young and very healthy. They follow a healthy lifestyle. He is the least forthcoming of my interviewees, and must be encouraged to share during the interview. He appears quite hard on the outside, and very abrupt. He also suffers tremendously from anything that threatens his control over a situation. He tries very hard to approach tasks with a lot of preparation so that nothing will go wrong and when it does, he loses control easily.

Earl is a mass of contradictions. Although appearing cold and removed, he, in fact, desperately misses the communication with his wife. Due to his controlling nature, his children actually may be closed off from helping very much. He doesn't ask them for help. Perhaps he doesn't value their skills. The son who was present in the next room during the interview said almost nothing, as I came in and when I departed. He didn't act like a grown up. He kept his distance. Why? It is not clear that the family members, who have now moved in to help Earl, will make matters better. There may be problems with the grandchildren accepting their grandfather. He is not an easy man.

The PTSD causes him to become very impatient and angry with his wife, and she is at a point where she gives it back to him. When I ask if he sees himself differently, he says, "My temperament has changed. I'm sort of impatient and like I said before, angry. Just the situation is challenging." He attends a support group, which has a separate session for the dementia spouses at the same time. But his wife doesn't want to be with that group, and wants to be in the group with her husband. At one of the sessions, he got very angry, and possibly struck her, although no one saw it specifically. "I got all angry and threw her in the car and came home." He knows it was inappropriate, but he loses control.

The toxicity is obvious, and besides the PTSD situation, they have been isolated, until recently, and she has difficult behaviors. There are adult children, and one of them has a family and recently moved in with the couple. The presence of the family, however, may not be as calming as is hoped. PTSD in either caregiver or receiver is not a good mix with dementia.

6. No External Services.

Of the remaining toxic situations, Kay (I-19) was the only interviewee caught in a toxic dependent symbiosis, and not receiving any services. Kay is young, only 65, but she has been in the caregiving role for up to 24 years. Her husband's disease is not diagnosed clearly, but it is another dementia, and he retired early from teaching to become a recluse in his own house, with Kay bound to him and the house as well. For some years, she did go to work, in order to finish putting her daughters through college, but they are gone now, raising families of their own, and she is still trapped at home. One of the few things she does for herself is attend a support group, but has to hurry home, because he will wonder where she is.

Again, during the interview, she is unable to really come up with any options for herself, but instead wavers back and forth, a distinguishing characteristic of this Stage 5-A. She has been caring for him for so many years, first angrily, thinking he was just depressed or lazy, and then almost guilt-driven, because he has dementia, although not the Alzheimer's type. Now she seems to believe he is entitled to his dependency, perhaps because there is an official diagnosis, whereas before the diagnosis, she felt he was just being demanding. She doesn't want him to be so dependent on her, but can't commit herself to doing anything to wean him. This is one of only two interviews not conducted in the home of the caregiver.

During the twenty years that he has just stayed home, but generally was able to hide his deficiencies, Kay says her pattern was to be out of the house. 'Every day I had something. Yes. I really realize when I look back … and I try not to look back too often … because you could really kill yourself …" However, in the last four years, he has suffered much more serious cognitive decline. When he started the Parkinson's drugs, he improved in many ways, but he is still terrified of his cognitive losses. She is bound to him, and feels the isolation.

Kay is very emotional as she shares her thoughts about the change in her role, her identity. "It's 24/7, the spousal part and you don't have what you had. You don't have that connection anymore like you're part of that universe...you're both connected and all of a sudden, you're not connected." This expressive quote clearly shows the demarcation brought about by the cognitive disorders. The couple is disconnected from an outside world. No longer part of that larger social community, that universe of couples. “I think if my friends were still on the Island … I feel so isolated and alone and so incredibly lonely and quiet. It’s like living with a mummy and I always have to take this mummy with me like a comedy.” One reason she had joined the support group was because one of the women in the group had become her friend. But how do you have a friendship with another caregiver? Neither of them really have time for each other.

Since he refuses to go to adult day care, the support group, or have in-home help, there really isn’t any way for her to make time for herself.

> He’s very attached to me. I feel myself more and more and more pulling away and it’s very guilt inducing but I just want him to go away sometimes. . . I think it’s terrible because I think I’m supposed to love him no matter what … for better or worse … this is … I have no problem living alone … I think I could live a lot happier alone but I don’t want to abandon him. He wouldn’t do it to me and I just feel I should take care of him. You get sick and somebody bails out on you … that’s not right.

For 20 years she has been trying to decide what to do, whether to leave or stay. By default, she stayed, and she still doesn’t know the answer to her question. She is still locked in his holding pattern.

These are the factors that indicate toxicity. Having one or two of them might not be enough to have true toxicity, but most of the couples in Stage 5-A had most of the factors. The rest of this chapter will look at the other possible direction for couples in the dependent symbiosis, the mediated dependent symbiosis.

Stage 5-B: Mediated Dependent Symbiosis

All of this research would be utterly pessimistic if it weren't for the fact that spousal dementia caregiving does not have to end in toxicity. Twenty-eight of the interviews were with couples headed in a different direction, owing to mediating factors. These factors are conditions that exist as a "safety net" for these caregivers due to previous experience, a supportive network, and outside services. Stage 5-B of the symbiotic spousal relationship shows that different direction and expresses the most common mediating factors for toxicity. In this stage, the relationship is still dependent, and weakening to the caregiver spouse (host), but that same spouse is bolstered by the mediation, thus preventing the toxicity shown in the 8-A cases. These spouses still express a sense of humor, a certain level of confidence in their own ability to solve problems, a conservative optimism about their lives, a love for their families and friends, and a desire to take the challenge of dementia, one day at a time. Three of these caregivers already had gone through the recent death of their spouses, and two had placed their spouses in a nursing home. Their memories of their days at home with their dementia spouses were still somewhat raw and painful, but even in these cases where they had passed through the full range of the dementia, the symbiosis had not become toxic owing to mediating factors.

Factors Mediating Symbiotic Toxicity

1. Length of Marriage

Eleven of the forty couples had been married 55 years or more, with the longest duration being 64 years. None of these couples were in a toxic stage. However, seven of the nine toxic symbiotic couples were married 40-54 years, thus, as a mediator, length of marriage does not appear to be strong enough to save the symbiosis from toxicity. There isn't enough data to say that length of marriage mediates the effects of the symbiosis. However, it is probably safe to say that the oldest couples had the fewest behavioral problems. These dementia spouses weren't as strong as the younger dementia spouses, and therefore less disruptive, and easier to care for.

2. Supportive Adult Children Nearby

Ten of the symbiotic couples did not have supportive children nearby. The remaining 29 symbiotic couples were fortunate to have supportive adult children nearby. (Remember that one of the caregivers was not in a symbiotic relationship.) Lack of supportive adult children nearby does not associate with toxicity because all but one of the toxic relationships had supportive children nearby. However, of those toxic relationships, only two had strongly supportive adult children nearby**.** The difference between supportive and strongly supportive is subjective, but reflects the investigator's sense that the strongly supportive adult child often gives the caregiver respite, seldom criticizes the caregiver, regularly sees the couple, assists the caregiver with ADLs, and sometimes even chooses to live with the symbiotic couple in order to help them. There were six of these adult children in this sample.

The two adult children strongly supportive of a couple in a toxic relationship were the daughters of Maggie (I-11) and Kieran (I-36). In the first case, the adult daughter worked alongside her mother in the mother's business, often accompanied her mother and stepfather when they went out, and was a supportive shoulder for the caregiver spouse. Kieran's daughters were also strongly supportive with one living down the street with small children, and the other returning from college to live at home and help Kieran care for his wife. They provided constant respite for the highly stressed caregiver. Their help was not able to forestall the toxicity from developing, and, in fact, they probably were feeling the effects of it as well, in their personal lives, and in their general mental state.

The other four examples of a strongly supportive adult child nearby provide strong mediating factors for the effects of the increasingly dependent symbiosis of their parents. Judith (I-9), as was shown earlier in this chapter, had the live-in support of her daughter, son-in-law, and grandson during the worsening of her spouse's condition. When he could not balance himself anymore, and walk, the daughter suffered an injury trying to assist him up the stairs. This was the tipping point for whether the care receiver should remain at home. His physician pressured the caregiver to place him in a nursing home, and so the ultimate mediating factor, nursing home placement, was invoked.

Similarly, Christina (I-27) had the support of all of her children, but one of them actually became her father's live-in home health aide. This daughter moved back home, and quit her other jobs, in order to provide home health care to her father. The caregiver mother assisted the daughter as her spouse became more difficult to physically care for, and helped her daughter financially by paying her as she would a home health aide. When the two of them, together, could no longer give the physical assistance needed to keep the care receiver clean and comfortable, they also used the final mediating factor of nursing home placement. Even so, the whole family of four adult children came home when the father returned to his home to die, with the assistance of hospice care. The extent of this adult child support is unusual, and hard to quantify, but it does exemplify the category of "strongly supportive" adult children. Despite the ten years of spousal caregiving, the symbiosis of this couple survived without long term toxic effects, because the caregiver and the family knew when to make changes. That caregiver spouse continues to attend her support group to help other caregivers still caught in the dementia maelstrom.

Grace (I-38) also had to place her spouse in a facility because she could no longer care for him physically, having suffered a broken hip in a car accident when he still was driving. Since she could not drive, she allowed him to drive longer than he should have. While she was recuperating in a rehabilitation center, her only child, a daughter, and her son-in-law, had to step up and provide the step-father's care. This couple was the only family support Grace had as dementia overtook her spouse. She has moved to live closer to them, and they continue to be a strong source of support for her. His adult children from his first marriage, had nothing to do with him.

Another example of a caregiver spouse with strong support from her adult child is Kitty, (I-26). Remember that Kitty is the longest married of the caregivers at 64 years, and is 85 years old, still caring, at home, for her 89-year-old dementia spouse. As with Grace, Kitty does not drive, so she relies on her son and his family who live adjacent to her. This Italian family has strong family values and without the support of the extended family next door, Kitty would not be able to care for her spouse. Since the husband stopped driving at 79, the adult children have provided transportation.

Lawrence (I-14) is another 85-year-old caregiver who cares for his wife, with all of the ADLs, a task that can be daunting for anyone, but he has been providing care for 11 years. What has made this possible is the daily assistance of his adult daughter, a school district superintendent, who comes to her father's house every night, to help put her mother to bed. "My daughter at times has put her to bed by herself. I'm in here watching TV and she'll sneak in and put her in the chair, give her a gown, put her on the commode wait a while, take her off, walk her over to the bed. That's a physical thing. It's very physical … and put her in the bed."

All of the other cases of supportive adult children show many of the same characteristics, but not to such a great extent. All of the caregivers seemed to appreciate the adult child who supported them in their efforts, rather than criticizing them. It almost seemed that no support was preferable to the caregivers, than support with criticism attached. Adult children who tell caregiver spouses to "just put him in a nursing home" add tremendously to the caregiver's stress. The only help they can offer is a solution that is still, as yet, unacceptable to the caregiver, caught as he or she is in the symbiosis. However, if they are part of the dementia journey as with Judith's children, or Christina's children, then the decision for placement in an institution is shared; the burden, once again, lessened.

Even though, by themselves, the adult child cannot prevent the toxicity of Stage 5-A, they can help mediate the toxic effects of the dementia dependency. Some of the caregivers had children at a distance, and these caregivers were wise enough to know that they would need to move to be closer to this kind of support. Supportive adult children can make a move more than worthwhile.

3. Prior Caregiving Experience

Sixteen of the caregivers had prior caregiving experience, beyond the tasks of raising children, but of the toxic caregiver situations, only two had prior caregiving experience, and one of those only provided Instrumental Activities of Daily Living (IADL) support, not ADL support. The physical aspect of caregiving is very wearing for the adult spouse who has never assisted with ADLs previously.

Some of the caregiver spouses had an extraordinary amount of prior caregiving experience, which seemed to help them with the challenges of dementia caregiving. Moira (I-6) had the most references in her interview to prior caregiving experience. Her father lived with her and her spouse for 19 years, dying at the age of 94, still cognitively intact. She also provided care to her mother who suffered from strokes in her sixties. When a friend needed a mastectomy, she was the one who stood by her, escorting her to her appointments. Furthermore, as a grandmother, she babysits for her grandchildren. During the interview, it was clear that she was a model caregiver.

In her father's case, she lovingly provided care for those 19 years, but isn't sure she can do the same for her spouse. The cognitive decline bothers her, and her relationship with her spouse isn't good anyway. She has admitted to a rocky marriage. But it is clear that her prior caregiving experience makes it easier for her to be his caregiver, and assist with ADLs, if necessary.

In many of the prior caregiving experiences, the care was physical, and the disease robbed the patients physically, but not mentally. The caregiver spouse knows he or she can do the physical caregiving, but continues to worry about the cognitive issues. Elizabeth (I-7) cared for several family members. At 26 years of age, her twin brother developed a brain tumor, and her mother, a stay-at-home immigrant, who did not speak English, wasn't able to accompany him to the doctor's, so Elizabeth did. ". . . I was the one who spoke to the doctors, who did everything, so I was. . . Yes - I was born a caregiver." Later, her mother developed dementia, and Elizabeth was her caregiver for three years when the mother moved in with her, and then for another five when she was in a nursing home. Elizabeth has already borne a lot of responsibility for other loved ones, and now she faces it with her husband.

Elizabeth and Moira are not the only prior caregivers, for indeed many of the female caregivers identify themselves as lifelong caregivers. As Amy (I-1) said:

> And basically, I was always a caregiver anyway. I was like to my kids I was a . . . and then my mom, she lived to be 88 and my dad passed

> away, and I did all of her business for her, because she never handled anything and took care of all her medical needs and all of the stuff, so I am, you know, it is just what you do when you love somebody, whether it be your mother or your husband, or whatever.

Two of the 11 males interviewed admitted to prior caregiving experiences, though not as intense as what they currently face. Phil (I-40) cared for a hearing impaired son, and Wayne (I-34) cared for his developmentally disabled daughter, but in both cases, the caregiving was mainly advocacy.

Martha (I-33) admits that caregiving is part of her identity. She cared for her father, her mother, and her mother-in-law, and now for her husband. “I’m an excellent caregiver. . . You go from caring for your children right into this. I think that’s scary. Who needs me now?” She knows her time as caregiver for her spouse is limited. Soon he will not be able to swallow. It may be a relief when he goes into a nursing home, but at the same time, she has a lot of identity work ahead of her.

4. Support Group

Support groups have become a major source of information and assistance for caregivers. Traditionally, mainly adult child caregivers availed themselves of this service. Spousal caregivers usually would not attend these sessions because they were providing care to their spouses. However, new time formats and the addition of simultaneous respite care groups for the dementia spouse have made them more accessible to spousal caregivers. Of the forty interviews, only 15 caregivers never used a support group. (This is not representative of the population as a whole, because in order to get the sample of caregivers, the interviewer worked through existing contacts in the aging field, including support group leaders.) Of the 15 non-users, 8 would have used a support group if they had found one geographically near, had been able to drive, and had respite care for their dementia spouse. Location, transportation, and respite options were the three biggest barriers to accessing support groups by those who were not able to join a support group, but had a desire to.

Besides the accessibility barriers, a few of the caregivers chose not to come owing to their own personalities. Four of the caregivers indicated they had no interest in a support group, or felt they were too independent for a support group. It is interesting that two of those four caregivers were African American. Both Millie (I-13) and Lawrence (I-14) showed no interest in a support group. They were interested in services, but not a support group for themselves. Millie had family nearby, and Lawrence had a very supportive daughter who helped him care for his wife, so they were not isolated. The interviewer was unable to tease out why they rejected a support group. In Millie's case, it may have been time. She didn't have much free time, and if she had any, she wanted to sew. Neither of them were getting support from a church. The question is still open regarding why they both rejected support groups.

The other two caregivers who rejected support groups were very independent personalities. Wayne (I-34) said: "I'm my own worst enemy. I can do anything. I don't need any help from these … I know I shouldn't feel that way but I do. I'm a very independent person." Jill (I-31) has somewhat the same tone when she said, "I'll figure it out. If I want help, I'll ask for it. If I need help."

For those who were in support groups, the experience generally was positive, except for where there was a mismatch in the attendees. If younger caregivers felt overwhelmed by older adults, or if spousal caregivers felt overwhelmed by adult children, the experience was not beneficial. In those cases, the caregiver usually stopped going. However, for the majority of caregivers, the experience of the support group was very beneficial.

Reasons given for why the support group was beneficial to the caregiver include:

- An opportunity to talk to other people.
- Sharing of helpful information about how to handle challenges of caregiving.
- Bonding with other caregivers, which carries over to telephone and computer networking.
- Information and assistance from the support group leader.
- Safe environment where caregiver can speak his/her mind or "blow off steam" because the others will understand.

- Problem-solving climate where caregivers work together on solutions for specific problems, and provide encouragement to individual caregivers facing difficult situations.

Those were the most frequently mentioned descriptions of what the caregiver liked about the support group experience. The social element is quite strong, which is so helpful to those caregivers generally isolated at home. The support group gives fellow caregivers an opportunity to share their concerns, with those who really know what it is like to be a spousal caregiver all day, every day. That is why when the support group is too broad and encompasses adult children, it is not as successful as when it has a unified identity.

What is interesting is that this elder cohort, most of whom had never been in a therapeutic group of any kind, found the support group structure so important. Doug (I-18) was another very independent man, someone who didn’t even ask much from his children. He had been in his support group for seven years. It actually seemed out of character, yet the group had become an important part of his life. He referred to it as “counseling.” When his wife was first diagnosed, he learned about the support group and joined. He admits he doesn’t say too much, because his wife doesn’t cause all of the problems that others talk about. But, from the others, he knows what is coming, and he is preparing his condominium for her continued care. His stage is still commensalistic, and perhaps it is the support group that is keeping him from Stage 5A or 5B.

The question remains as to why this elder cohort, people like Doug, without any prior experience of group therapy, value their support group experience, and willingly continue. From a social identity standpoint, perhaps it is the support group that helps in the process of the caregiver building a new identity. These group members are all trying to redeem and validate their lives, and the connection with each other helps them do this. They understand the spousal caregiver identity. They validate each other in that identity. They also share the symbiotic experience of spousal caregiving. They don't feel that their symbiotic identity is isolated and confined to their homes. When they go to the group, everyone understands about ADLs, showering problems, losing patience, and so on.

Most of the interviewees emphasized how hard it was to really talk about their experiences except at the support group. Judith (I-9) is extremely verbal, and she explained this problem well in this quote. "Honestly, you can't just go out to lunch with somebody you have known all your life and talk about it. They have no clue." It is the experience of being a caregiver for a spouse 24/7 that most people don't really understand. There is more at stake than just the work required to care for the spouse. There is all the inner turmoil for the caregiver, and this is what the support group lets you talk about.

Returning to Doug (I-18), there is the concept of “milestone” or marker event, which he spoke of in his interview. He was the caregiver who did not yet want to use the “Safe Return” bracelet from the Alzheimer’s Association. For him, that was some kind of dividing line, and if he succumbed to using it, that would somehow prove the care receiver’s status was clearly worsening, and he wasn’t ready yet to admit that. Similarly, the milestone concept can be applied to attending a support group. It signifies that one is a caregiver, first of all, and, thus, in a different kind of spousal relationship. This is a very public signal.

Many of the caregivers spoke of not being ready for a support group. Rob (I-4) has attended some group meetings, but is not very comfortable. The stories that the others share upset him. “I went, and then I stopped going for four or five months, because we were busy, Florida, Christmas. I just wasn’t ready for it. I wasn’t ready for it.” In Rob’s case the wife is deteriorating so quickly that the support group cannot give him the answers he seeks, which frustrates him. This frustration often is the case for younger caregivers like Rob. It is hard for him to identify with the 80-year-olds who are also in the group. All of this has to do with his social identity, and his panic about not being able to control this change. Rob is actually in Stage 5-A, a toxic stage, even though he has attended a support group. In fact, all but one of the caregivers in a toxic symbiotic relationship attend a support group. Why does a support group mediate for some of the caregivers, preventing this toxicity, and yet fail to mediate for others?

Actually this question relates to all of the mediators. Caregivers in Stage 5-A may share many of the mediators, but still have some counteracting pressure that prevents the mediation. In Rob's case, the lack of communication with his spouse, the speed of the disease, his spouse's difficult behaviors all serve to subvert the therapeutic nature of the support group. Furthermore, he does not identify with the group, perhaps pointing out the toxicity of his situation.

Most of the caregivers in Stage 5-A are not regular attendees of a support group, and a few have given up on finding a satisfying support group experience. Maggie (I-11) works during the day so her attendance is sporadic. Laura likes the leaders very much but only attends occasionally. One of the topics she wants to discuss that the other members do not want to address is sexuality. Brenda (I-8) can't leave her spouse in order to attend. Kieran (I-36) can't find one for spousal caregivers that meets at night, because he still works. He isn't comfortable with groups geared to adult children because he can't relate to their concerns about their elder mothers, when it is his 56 year old wife that he is concerned about. Sarah (I-12) stopped going because she never got to say anything. The leader assumed she wouldn't want to since she had to bring her spouse with her, and he was in the same room. In every case of a Stage 5-A caregiver, there is something unsatisfactory about the support group experience.

Also, there are quality differences between support groups. The most successful groups meet once each week, so that there is consistency to the group. When the meeting is cancelled, the members of one successful group miss it so much, they sometimes call each other to fill in the gap. Adult day care sites often offer support group meetings to caregivers, and these generally seem successful. These would be held when the spouse is being tended to in the day care setting, so the caregiver has respite and can concentrate on the support group.

The role of leader is key, and it was clear that some leaders are loved and respected, while others are left behind. Giving everyone a chance to speak is very important, for several caregivers complained about certain members monopolizing the group, leaving no time for others to share. Again, the leader has to make sure that all attendees get some benefit from the group. These individuals, professional and educated, make a significant difference in the mental health of the caregiver and in the balance that should exist so that the caregiver is able to leave the group meeting, bolstered for another week of round-the-clock caregiving.

Karen (I-2) is one of the caregivers who derives a tremendous amount from her support group. “. . . we have a very bonded group there. We honestly do. I can’t believe how we have bonded. I mean we have gone out to lunch, the ladies, four or five of the ladies, have gone out to lunch. Joe and I have also gone out with a couple of the couples for lunch. We talk . . .” She has been attending for two years, and her group is very important to her. For Karen and others like her, the support group is their lifeline to a world that exists outside their symbiotic dementia caregiving experience.

5. Adult Day Care and/or Respite Care

Adult Day Care is the controversial appellation for one of the services designed with dementia care in mind. It is a respite service which provides two models of care for adults needing supervision. Social models offer a safe setting for persons with dementia or other frailties to join with other elders, for socializing, sharing breakfast and lunch, participating in crafts and games, engaging in physical activities. Sometimes, a children’s day care is part of the same facility, and there are intergenerational programs for the two populations. The number of participants is anywhere from 5-20, but because of the special needs of this population, the total is kept low.

Developing after social day care in the 1970’s, medical model adult day care tries to provide the same services listed above, but adds on a thorough list of medically supported services such as physical and occupational therapies and pharmaceutical supervision. Often, this type of service is covered by Medicaid or even long term care insurance, so the cost to the family is manageable. If the patient qualifies for Medicaid, then the medical model and transportation probably wouldn’t cost the caregiver anything, but Medicaid doesn’t usually cover the social models, so the caregiver must pay for those services, and probably the transportation as well. Whereas a social model might cost from $35 to $50, the medical model would probably cost upwards of $150 per day. The less expensive social model is the format most appropriate for the person with dementia.

However, if the person with dementia has other medical needs, the medical model is a good alternative, although more costly.

There are other respite care services offered in this region, sometimes on a sliding scale to caregivers, but as was reported many times in the interviews, there is a long waiting list, so it should not be viewed as a short term solution. Eight of the respondents when asked what kind of service they would create for caregivers, indicated respite services. Some long-term care facilities are starting to offer overnight respite services for caregivers who need to get away for a weekend or longer, but these are not well known or advertised, nor would they work with many dementia care receivers, because the change of environment would be very unsettling.

Some of the questions raised by Farberman et al., (2001) and Farberman et al., (2003), documented the lack of information about adult day care, and the low participation rate for adult day care. However, when families do use adult day care for their relatives with dementia, they usually are very positive about the service. Still, usage rate is low, and public recognition of the service is low. In the current study, there were several open-ended questions about services for caregivers and care receivers:

- Do you use any of the services available to caregivers?
- How did you learn about this service?
- What made you decide to ask for this service?
- Is there any available service that you purposely do not use? Why?
- If you could design one service, which you currently do not have, what would it be?
- Is there any service that the county should provide to make it easier for you to cope with caregiving?

If the respondent did not mention adult day care, he or she was asked about it specifically.

All of the respondents had heard about adult day care, which is a very positive sign. Again, this sample is not representative of the population as a whole. As shown above, 25 of the interviewees used a support group, so they often heard about adult day care. Some were advised by their physicians. Millie (I-13), the African American who was not interested in a support group had met with someone who explained the services available to her, including adult day care. “She said for maybe for the first day or couple of days I would have to take him myself to get him used to it and then they have this bus to come pick him up. I thought about that … one thing to another … I just haven’t done it.” She did not sound convincing about her interest in using this service. Some of her reservation may have been the fact that social day care charges participants a fee. Financial consideration kept many of the caregivers from using adult day care as much as they would have liked, and sometimes prevented them from using it at all. This table shows the results of the research concerning adult day care.

Table 2: Use of Adult Day Care by Caregiver

Knew About Adult Day Care	40
Tried Adult Day Care	27
Positive Reaction	19
Negative Reaction	2
Kicked Out*	3
Spouse won’t go	3
Never Tried Adult Day Care	13
Prefer In-Home Services	3
Probably Will Try Later	6
Probably Won’t Try	4

Note: Three of the interviewed caregivers knew about adult day care and had tried it for their spouse, but were asked to leave, due to aggressive behaviors or incontinency. All three of these caregivers were in Stage 5-A, the Toxic Dependent Symbiotic Stage.

As Table 2 shows, the majority of respondents were very positive about adult day care, and even if presently not using the service, they were planning to use it when their spouse was ready, or when they had the financial means. Those who were positive offered these reasons:

- Benefits from kindness of the day care director.
- Provides recreation activities such as singing and dancing.
- Gives dementia spouse enjoyment of the company of others.
- Projects home-like environment.
- Offers activities dementia spouse can do, replacing those he/she can no longer do.
- Relieves monotony of staying home, sleeping too much, and being very sedentary.
- Provides support and information for caregivers.
- Gives respite to caregivers so that they can do other things.
- Delivers physical and medical care to dementia spouse if medical model.
- Provides much needed "attention" to the care receiver.
- Improves mood of the dementia spouse for the day and tires them out for sleeping at night.

The caregiver who perhaps best personifies the benefits of the program is Dan (I-29). This 78-year-old caregiver lives with his spouse in a somewhat isolated rural area. Although he had tried to move with his spouse to California, and live with a daughter, the spouse resisted the change, and deteriorated cognitively. Now he is committed to keeping her at home. To help him with this, he has employed an aide to help him in the morning, three times a week. Every weekday his spouse goes to a social model adult day care provided as a service by his local community. Besides serving as an outlet for his wife, and respite for himself, the day care site offers a support group for caregivers. His future plans include adding a room to his home for a night-time nurse's aide. Although he does not have adult children close by, he has daughters who live near enough to visit them from time to time, on weekends.

Actually, he wishes the day care was available on weekends, just showing how important this service is to his life. When asked if it was easy to get her to go, he agreed with most of the other caregiver stories. Dementia spouses do not want to go to adult day care. It doesn't matter what you call it, they do not want to go. It isn't clear why they are so opposed to this service, but they appear to sense that it is all older people, and perhaps are fearful that their caregiver will leave them, and not return. However, persistence is key, as well as timing. “For the first month she didn’t want to get out of the car. ‘I don’t want to go to that place.’ I say, ‘Come on. I got to talk to Mary (director) about something.’ Gradually … she (Mary) says this is not unusual. It’s a change and they like familiarity.”

Dan also makes it clear that the Director, Mary, is the key to his success as a caregiver. He refers to his first hearing about the day care as a “blessing,” echoing many of the other caregivers. He can’t understand why more people do not use the service. “I have a suspicion that there are a lot of people that would love to know about it that don’t know about it.”

The persistence shown by Dan in getting his spouse to go to adult day care is significant, because in three cases, caregivers wanted to use day care, but their spouses would not go in to those sites. Even if they got them in once, and the spouse seemed to enjoy it, the spouse then said, “I’m not going back there with old people.”

Most spousal caregivers who are not using adult day care, say their spouse is not yet ready. There does seem to be a readiness moment, because often caregivers told me that the first time they visited an adult day care, the spouse hated it. Yet within a few months, and a visit to another site, the spouse was more willing. **However, in some cases, it is the spousal caregiver who is not ready.** They see their spouse as symbiotic with them, and do not think the spouse will go into a strange group. As was said earlier, dementia spouses do not like to go, but over time, develop a pattern of going, and seem to benefit from the structured stimulation. Symbiosis does work against placing the spouse in any outside facility, but the majority of caregivers eventually were able to do this effectively.

The well spouse’s concerns are important, because these concerns, as well as the symbiosis, keep them from accessing this service. Will (I-17) is still in the early stages of caregiving, just now starting to attend a support group. When asked about adult day care, he said: “I’m very concerned about it because I wouldn’t even know how to approach it with her. At some point, I’m not looking forward to it, but we’re going to have to consider it.” In his mind, the image of adult day care just doesn’t match the image he still has of his spouse. Just as he can't yet imagine her in an adult day care, the dementia spouses do not always see themselves as needing adult day care. Their self perception does not match what their social identity will tell them when they enter an adult day care. As Maggie's spouse tells her when she takes him to visit an adult day care, "No they are all much further gone, than I am." He isn't ready for this new social identity, and perhaps Maggie isn't either.

Regardless of how dementia spouses get to day care, they seem to benefit, and the caregivers seem to love it. Only two caregivers who tried adult day care, did not like the experience. In one case, a social day care, the caregiver spouse didn't feel that they stimulated his wife enough. He wanted more activities. The other case involved a dementia spouse with an unusual form of dementia, a younger care receiver, and the medical model day care staff did not support the well spouse, but rather actually worked against the medications being used to treat his unusual form of dementia. As perceived by the caregiver, she got respite, but the spouse would come home ready to battle her, due to the encouragement of the day care staff.

One of the sad revelations of this research was that three caregivers in the toxic stage of symbiotic dependency were unable to use the adult day care service, which would have given them respite from the toxicity. Each of the care receivers was turned away from their day care attendance because of aggressive behaviors or incontinence. The saddest of these was Brenda's (I-8) case, because she really needed the respite. However, her husband did physically pin her down, and was just too physical for the usual day care setting. What was making their symbiotic relationship toxic, was also hampering their ability to be in any social setting.

There is no stronger argument for the mediation provided by adult day care, than the words of Phil (I-4), whose wife goes to a social model 3 days a week. "Personally I feel I'm a prisoner. If it wasn't for the day care I think I'd blow my mind."

6. In-Home Supportive Services and Long Term Care

In-home services were also evident in the homes of twenty of the respondents, which is not surprising if you recall that this spousal caregiving is every day, all day and night. Usually it is the adult child who is pushing the caregiver spouse to get some help for the dementia spouse. Whereas many adult children do not know about adult day care, or respite programs, they do know about home care. Even caregivers not currently using home care services, expressed a general interest and willingness to have this kind of service. (See Table 3, p. 134, for the list of in-home support services used by caregivers.)

Two caregivers registered one of the problems associated with home care. What does the caregiver do while the personal care aide or other health care worker is in the home? This is the symbiosis speaking. Moira (I-6) says: "But it is funny, when the home health aide comes, I look, and I say, what is she going to do? Now that she is here?" Moira now has the aide coming because her husband was just released from the hospital. Having time to herself is so rare, that it takes time for it to occur to her that she can leave while the aide is there. Rob (I-4) usually analyzes all of his moves before he makes them. In this case, he knows in-home care would give him a chance to separate from his spouse who is crying all the time. However, he can't stop himself from considering the down side of in-home aides. Will she speak English? Will I have to drive her? Will I have to watch the clock and make sure I am back when she leaves? Should I build an extra apartment for the aide to live in? Will she show up? These are the issues surrounding home care, and they frighten Rob. To him, this cure seems worse than the disease.

In contrast, most of the twenty people using home care were very satisfied with their respite workers. If there was a problem with the first Personal Care Aide (P.C.A.) placed, the caregiver went back to the agency, or to a different agency until he or she found one that would be compatible with his spouse. Because these aides spend so much time in the home, personally caring for the spouse, the caregiver spouse is looking for a nurturing, responsible aide, one who will be kind to the spouse, one who hopefully, will like the spouse. For those in long term situations like Lawrence (I-14), Martha (I-33), and Amy (I-1), the in-home health aide is almost part of the family. They dread losing that special aide who provides so much physical care for their spouse. Spousal caregivers know just how much effort it takes to shower a dementia spouse or to coax them to eat, and they value the aide who by doing these tasks, relieves them of part of their burden.

Dina (I-15) would be in a hopelessly depressing situation, one threatening her own sanity, if it weren't for Melissa, the young personal care aide, who comes as a companion three days a week for her dementia spouse. This young woman greets the spouse with warmth, takes him to movies and lunch; helps him get dressed; drives him on errands, thus sparing Dina some of the intensity in their relationship. It is a good day for both of them when this young woman comes.

Wayne (I-34), who can't bring himself to join a support group or enroll his wife in an adult day care program, does have a young woman coming into his home on Friday mornings, to help clean, through a county-provided in-home services program. But the positive side effect is that she gets along very well with his spouse, and he is considering asking her if she would be willing to be a respite worker when he needs to go out. Then he can get out for awhile, independently, without bothering his daughter, and his wife can enjoy the companionship of someone she relates to well.

How many of the caregivers use this mediating factor in their caregiving structures? This table shows that caregivers are split in half exactly, with 20 getting some level of home care services, and 20 having no home care services so far. "So far" is an important caveat, because it is likely that the remaining twenty caregivers will experience home care or institutional long-term care at some point in their caregiving journey.

Table 3: Use of In-Home Support Services

Caregiver Used In-Home Service	20
Steady, Regular Use of P.C.A.s	9
Light or One-time Use of P.C.A.s	5
Use of Respite Service	2
Use of Hospice Service	2
Use of EISEP Service	1
Use of VA "Home Support"Technology	1
Caregiver Has No In-Home Services	20
Probably will use In-Home Services	13
Probably will not use In-Home Services	7

Again, in the toxic dependent symbiotic relationships, only two of the 10 caregivers have in-home services, with a third one trying County Respite and having her spouse reject the respite worker. In a few cases, money stands in the way, but usually it is the toxicity of the environment itself which prevents the spouse from wanting to bring a stranger into the home. Brenda (I-8), for example, states: "And you know, like, I haven't done that yet. My kids keep on saying, you've got to do it. Especially now, with the. . . It's very hard . . . I wouldn't want him to get physical with anybody." She says she worries about that, "more than anything." These caregivers worry very much about how their spouse will react to a stranger, and then, of course, they are uncomfortable having a stranger in the midst of their symbiosis, their marriage which is on its downward spiral. What they don't see is that those who were able to take the step and allow in a stranger also usually were saving their marriage from the toxic abyss, as in the case of Dina.

Nursing home placement is really a further extension of in-home care, because it is giving up control of the caregiving to a professional caregiver. It is definitely putting a wedge in the symbiosis, and in some cases saving the relationship as well. Caring for her mentally ill spouse was almost destroying Bella (I-37), not just because of her husband's provoking and argumentative behaviors, but also owing to the polarizing effect of the day care staff on the couple. Although it did not solve their problems, when Bella placed her husband in long-term care, it moved the battlefield out of their house, and gave her one place she could be at peace. This was an unusual case because it was related mostly in retrospect.

Another case shared in retrospect was Christina's (I-27), because her spouse died before the interview. She used her daughter as the health aide, and was able to extend the time she could care for her husband at home. The length of time spent caregiving was ten years, with her daughter's presence in the home the last three years to help with the physical and mental decline. "It wasn't like he was fighting me but he just couldn't help and his … I used to say he was like a cement statue. Trying to move … to get his legs he would sit on the edge of the bed and I'd have to do this and I felt it in my back and I don't have such a great back anyway but …" Even with her daughter helping out, Christina did have to place her spouse in a long-term care facility. “The worst time was the last two months in here, last year.”

> Before he went in, we had his name on the list at “Beautiful Rest Home”. They just didn’t have a bed. He was getting very combative. He bit my daughter when she was trying to toilet him. He bit her on the shoulder and … you’d get him in the shower and you’d be afraid something was going to happen. There was a glass door on the shower so two of us used to go in. My daughter and I used to go in together … tried to keep him calmed down. At that point he was hating it.

So, Christina and her family decide that he should go into a nursing home.

> When he went into the nursing home which was the worst experience I ever had, although they were wonderful, I could never recommend a nursing home too highly. The doing it was awful . . . He lost 20 pounds in a month. He went on hospice for 3 months; came off hospice at the beginning of April and then went back on hospice at the beginning of July. He lost 100 lbs altogether from when he went in. In 8 months. He ate, except toward the end he stopped eating and drinking.

The nursing home experience was very trying for the caregiver, but she says, “I think my daughter and I had really gotten burned out. It was too much.” She knew he had to be in a facility. At the end, she utilized another service, Hospice at Home, and brought him back to their home to die, with his family around him.

Although some theoretical frameworks suggest that nursing home placement is one of the three transitions of caregiving, in the symbiotic framework, it is really just a part of Stage 5-B, because it is one of the mediators that can prevent the relationship from becoming toxic. When Christina’s husband bit her daughter, they were at a tipping point. They probably already had passed the tipping point, but their ultimate choice to place him in a nursing facility was an attempt at sanity. At 72 years of age, Christina had to protect herself, her mind, and her body.

The symbiosis of the couple did not stop because of the placement, but it was mediated, so that it wouldn’t endanger the spouse. Christina went on to give him a hospice death, in his own home, where the interview took place. There are echoes of his life there, but Christina is moving on, traveling to be with friends, taking time for her own children, and still attending the support group that helped her through so many months of pain.

None of the spouses were eager to talk about nursing home placement, usually holding it off as long as possible, but most of them could see that it was in their future, or some other kind of elaborate home care structure. The females really could not do all the physical care their husbands were ultimately going to need and had to face the reality of nursing home care. Some of them would pray that they would both die, together. Others would pray that they would outlive their spouses so they could care for them. Several of the men were truly committed to keeping their wives with them. Lawrence (I-14), at 85 years of age and 11 years as a caregiver, said, “I’m going to keep her with me as long as I can.” Doug (I-18), at 75 years of age and 7 years as a caregiver, said, “The future is pretty much … I’ve just got to live through it. I don’t know … the one thing I don’t have covered is if something happens to me.” He has planned for her care at home, but can’t quite figure out how to keep her there if he dies first.

These then are the prime mediators for the potential toxicity of the symbiotic dementia caregiving relationship. One final question would be if these mediators can work after the fact, when a relationship has become toxic already, as in the case of the ten of the forty interviews for this study. The answer should be yes, because it did seem that a few of the caregivers had experienced the toxic symbiosis, and then moved to make a change, as with Judith (I-9), Bella (I-37), and Christina (I-27), cases that help us understand what happens at the end of the caregiving journey. All found nursing home placement to be the means for maintaining their own physical and mental health, during the increasing toxicity of their spousal caregiving.

Table 4: Stage 5-A Caregivers and any mediating factors existing in their caregiving.

	Years Married	Supportive Children	Prior CG Experience	Support Group	Adult Day Care	In Home Services	Long Term Care
Rob	42	Mild	No	Yes	Yes	No	No
Brenda	54	Yes	No	No	No	No	No
Laura	40	Mixed	No	Yes	Yes	No	No
Maggie	3	Yes	Yes	Yes	No	No	No
Sarah	51	Mild	No	Yes	Yes	No	No
Earl	50	Mild	No	Yes	No	No	No
Kay	40	No	No	Yes	No	No	No
Eddie	50	Yes	No	Yes	Yes	Yes	No
Sue	51	No	No	Yes	No	No	No
Kieran	30	Yes	No	No	No	Yes	No

Table 5: Stage 5-A Caregivers and Factors contributing to toxicity.

	Isolation/ No Trans.	Difficult Behaviors	No Spousal Commun.	Unsupportive Children	CG Poor Mental Hlth.	Few External Services
Rob	No	Yes	Yes	No	No*	Yes
Brenda	Yes	Yes++	Yes	No	No*	Yes++
Laura	Yes	No	Yes	Somewhat	Yes	Yes
Maggie	No	No	No	No	No*	Yes
Sarah	No	Yes	Yes	No	No*	Yes
Earl	No	Yes	Yes	Somewhat	Yes	Yes
Kay	Yes	Yes	No	Distant	No*	Yes
Eddie	Yes	Yes	Yes	No	Yes	No
Sue	Yes	Yes	Yes	No	Yes	Yes
Kieran	No	Yes++	Yes	No	No*	Yes

*=Their mental health was tipping toward the “poor” rating, due to their circumstances.

+=More significant rating in this category.

CHAPTER VI: UNEXPECTED FINDING RELATED TO MEDICAL INTERACTIONS

The primary grounded theory derived from the interviews with spousal dementia caregivers has now been set forth in Chapters 3 – 5, the theory of symbiotic dependent caregiving. However, early in the research, a second, unexpected finding surfaced in the interviews. This finding grew out of questions meant to uncover caregiver stress, since the original question involved exploring the reason for high burden levels in the middle stages of caregiving.

Caregiver stress was actually coded 1,449 times in the forty interviews. While searching through the codes that co-occurred with caregiver stress, most of the factors explored under the heading of symbiotic dementia caregiving, showed up. These factors were also common in the caregiving burden literature. However, there was one new factor that was generally absent from the burden literature, and that factor was "medical interaction," which occurred 345 times and was cited in all 40 interviews, referring to any interaction with a physician, hospital, nurse, social worker, or other health care professional (HCP). Since it was not one of the critical issues found in the preliminary research about stress and burden for caregivers, it grew into an **unexpected finding**. Not only did it show up frequently in the interviews, but often it was part of a very dramatic portion of the caregiver's story.

By itself, medical interaction is not always a stressor. Some medical interactions are positive, and some are neutral. In a recoding of the original 345 citations, 79 were considered neutral interactions with neither a positive or negative effect on the caregiver; 117 were recoded as positive interactions; and 150 were recoded as negative medical interactions. Of the 40 interviews, 33 had citations for negative medical interaction. (See Appendix VII.)

There were 9 interviews with higher than average negative medical interactions, unbalanced by a similar number of positive or neutral interactions. The interviews with the highest number of medical interactions, were Rita, Brenda, Judith, Maggie, Annalise, Sue, Martha, Kieran, and Bella. These 9 interviews become the most relevant for a discussion of this unexpected finding, the link between negative medical interaction and caregiver stress. Since coding is subjective, all of this data is merely suggestive, but reading the citations shows how extreme these negative medical interactions can become, and how agonizing the results may be for the caregiver.

Furthermore, many of these stressful interactions occur near or during the time of diagnosis, which is a crucial stage in the symbiotic theory of caregiving couples. The caregiver and care receiver already are greatly stressed at that time, because they are beginning to comprehend that the change in their mutualistic symbiotic pattern is lasting, and increasingly downward in its trajectory. This dawning awareness challenges both of them to their core, and makes them vulnerable to external stressors, such as the negative medical interaction. If the well spouse, the caregiver, is not taken seriously at this time, it is doubly provocative.

Before looking closely at this study and its revelation about medical interactions, a review of literature pertinent to this finding is helpful, because the topic has surfaced to some extent in the gerontological literature, although not in the burden literature. First, there is the topic of diagnosis of dementia, viewed from a psycho-social perspective. Given that the medical diagnosis for dementia is complex, owing to the variety of types of dementia, and that some can be co-occurring (ex. Alzheimer’s disease with Multi-Infarct Dementia), the physician faces a difficult task just trying to be correct. However, the greater challenge is what he or she communicates concerning the diagnosis. Whatever the physician actually says, the patient and the spousal caregiver if present, hear Alzheimer’s Disease, and according to Goodwin (2002) thinks that first, the disease is incurable; secondly, it will progressively destroy the patient’s mind leading ultimately to death; and third, it can be inherited. This level of negativity within one diagnosis is almost too much for both spouses to bear. Thus, the nature of the communication is inherently fraught with mine fields.

In the early 1990’s, studies (Haley, Clair, & Saulsberry, 1992; Connell & Gallant, 1996) started to appear looking at the medical interaction during the diagnosis of dementia from a caregiver’s standpoint and found specific concerns: insufficient information from physician, vague diagnoses, and insufficient referrals. Focus groups with primary care physicians (Boise, Camicioli, Morgan, Rose, & Congleton, 1999) were held to explore how these physicians approach the diagnosis of dementia, as well as to identify obstacles to a dementia diagnosis for primary care physicians. One relevant finding from this study showed that physicians often shy away from a dementia diagnosis, even though they see cognitive changes. They employed what might be called “watchful waiting” because they did not see the value of an early diagnosis. They preferred to treat those health problems which they considered a higher priority, with dementia at the bottom of the list.

These same focus groups also showed a negative reaction toward ordering imaging tests, and unless pressured by the patient or family, these physicians did not like to refer to specialists. When pushed for a diagnosis, the physicians would often say dementia, instead of Alzheimer’s disease, feeling the specificity was not useful. One physician actually used the word “stigma” in explaining why he would not use Alzheimer’s disease but the more generic term of dementia, which didn’t carry as many negative stereotypes (Boise et al., 1999, p. 462).

Following up on this study, Carpenter and Dave (2004) reviewed the literature for guidelines on best practices for revealing the diagnosis, and found that practice guidelines often did not reflect the actual experience of the diagnosis as reported by physicians, patients, and family members. The authors argued that process issues involving all aspects of the face-to-face experience of the diagnosis are not clearly understood by practitioners. This research also raises the topic of cohort differences, and that the preferences of the older patients may not be the same as the younger patients, or their spouses. Passive involvement may be ceding to active participation as one goes down the age ladder. Indeed, the current study shows that younger caregivers experienced more negative medical interactions, because they tried to be involved.

Connell, Boise, and Stuckey (2004) continued using focus groups to look at the topic of diagnosis, but in this study included caregivers. Whereas physicians preferred to hold off on the diagnosis (Boise et al., 1999), caregivers reported that they wanted a diagnosis because they could then be more patient and understanding of their spouse's behaviors. Caregivers also expressed frustration over not being able to get a diagnosis, and not being taken seriously by the physician.

Similarly, a study looking at the cross-cultural aspects of perceptions regarding the diagnosis of dementia (Mahoney, Cloutterbuck, Neary, & Zhan, 2005) found that African American, Chinese, and Latino caregivers reported their community physicians also reluctant to diagnose Alzheimer's disease or to refer to specialists. Furthermore, the African American respondents especially reported feeling disrespect from the physicians regarding the caregivers' concerns about memory loss.

Continuing to probe the literature, what makes physicians so opinionated and "testy" about the diagnosis of dementia, or Alzheimer's disease, to patients and their caregivers? Fortinsky, Leighton, and Wasson (1995) explored the physician practices using vignettes to assess how physicians would handle the problem. They found them generally unwilling to tell the older female patient in the vignette the diagnosis, but would disclose the disease to the adult daughter in the vignette. Physicians also stayed away from actual mini-mental assessments in the office, and were more comfortable ordering laboratory tests. Clearly, there was a discomfort level operating for these physicians.

Part of the problem for the physician is related to the larger problem of determining health care for patients who are mentally incapacitated, another direction in the literature on medical interactions (Dresser & Whitehouse, 1994; Pearlman, 1996). When physicians face cognitive impairment, they face legal as well as ethical challenges. If they cannot get an accurate history from the patient, or if the caregiver is sharing information inconsistent with what the patient is saying, who do they believe? This uncertainty often leads to feelings in the physician of frustration and uncertainty (Adams, McIlvain, Geske, & Porter, 2005). When the patient has seen the physician over many years, the diagnosis is confounded further by the length of time of the relationship, causing the physician a sense of personal loss (p. 231).

This question of competency forces physicians to consider the role of the caregiver. Whereas traditionally, the dyadic relationship between physician and patient tends to be the rule, when there is incompetency, or the question of incompetency, the relationship often grows to a triad, with a spousal or filial caregiver present as well. As was noted previously in this study, well spouses often see this as a sign of their changing status, to a commensalistic couple rather than a mutualistic couple. Caregivers do not seek out this new role, but they do recognize its necessity. Physicians are not as quick to see the advantage. Haug (1994) described this caregiver as “the hidden patient,” drawing on the Hasselkus (1992) study which focused on the caregiver as the interpreter for the doctor-patient interview. Haug (1996) goes on to carefully describe the elements in the interaction between doctor and patient, with one of them being the presence of the caregiver. She writes of the possibilities for improved care as the “triad” of patient care develops, with the caregiver being respected as part of a team. A nursing case study (Williams, Keady, & Nolan, 1995) emphasized how important it was for the health care provider to provide enough information to the caregiver, and to let the caregiver take the lead in how much outside support is needed during the progression of the disease.

This recommended respect for caregivers and their role in the physician-patient relationship is balanced by Barone, Yoels, and Clair (1999). Their study returned to the physician perspective, and addressed how physicians view the triad situation. First of all, they acknowledge that it changes the physician-patient relationship, as it may lead to a loss of intimacy between physician and patient, decrease participation from the patient, and cause the beginnings of coalitions between doctor and caregiver against the patient. The tone of their paper is cautionary, and serves to balance the perspective that welcomes caregivers into the physician-patient relationship.

Another topic related to this triad relationship, is the topic of caring for the caregiver. Haug’s “hidden patient” is the recognition that the caregiver is under tremendous stress in the new role, and spousal caregivers are also aging, developing conditions which physicians may pick up on when they communicate with them during the office visit with the dementia spouse. How much should physicians concern themselves with these extra or “hidden patients?” Although O’Brien (2000) advocated in an editorial for physicians that they “support and bolster” family caregivers, including paying attention to the caregiver’s health, in order to better care for the patient, a later longitudinal study (Musil, Morris, & Warner, 2003) found that physician support for caregivers declined over time.

Part of the problem contributing to this apparent disconnect between what physicians are urged to do and what they actually do, are the myriad rules and guidelines enforced today by Health Maintenance Organizations (HMOs) on the practices of primary care physicians. The actual time spent with patients is closely circumscribed by such HMO guidelines (Adams, McIlvain, Geske, & Porter, 2005; O'Brien, 2000). The triadic interaction requires more time than the dyadic interaction, especially if the physician is supposed to be dispensing care, concern, and information to the caregiver, along with prescriptions for the patient. This pressure of time encourages the physician to move quickly, and perhaps not expect to accomplish very much of what was urged by O'Brien, above. Glasser and Miller (1998) found that physician and caregivers agree that the management of the patient issues were covered during appointments, in a satisfactory manner. However, caregiver concerns and contributions were not well addressed by physicians, from the perspective of the caregivers, although the physicians rated themselves more highly on this subject. Caregivers want, and perhaps need, more from physicians.

A critical issue not covered in the review of this literature was the gendered nature of the medical interaction. As will be shown on the coming pages, this study found women more adversely affected by the tone of medical interactions. In fact, as reported in a brief article published by the American Society on Aging (Hatch, 2005), there is some research that shows the concerns of older women tend to be more "trivialized" during medical encounters (Davis, 1984; Sharpe, 1995; & Munch, 2004.) If this is the case when the older woman is the patient, it strongly suggests this may carry over to the triadic medical interaction, when the caregiver is a female.

Whereas most people would think that the doctor or social worker should be a source of support for the caregiving process, for all the reasons reviewed in the literature, interactions with them actually may contribute to caregiver stress, not because the topic of the interaction is difficult or painful, but because the tone and content of the interaction often is perceived as disrespectful by the caregiver spouse. The range of the perceived disrespect, from somewhat mundane comments to outright venom, will be shown in this chapter, along with the caregiver spouse's reaction to the disrespect.

The recoding of negative medical interactions included the following descriptive categories of interaction:

- Early Disregard for Caregiver's Concerns by Physician (15 citations)
- Incomplete Information from Physician or other HCP (12 citations)
- Office Staff Communication (8 citations)
- Lack of Cooperation from Physician, Office, Other Health Care Professionals (HCP) (10 citations)
- Neurologist Lack of Rapport with Caregiver (12 citations)
- Underestimating effects of dementia by HCP (10 citations)
- Lack of Support from Physician or other HCP (14 citations)
- Poor Medical (Physician) Care (19 citations)
- Not Meeting Caregiver's Expectations for Treatment (1 citation)
- Medication Issues (16 citations)
- Poor Health Care Facilities (2 citations)
- Quick-to-Diagnose (HCP) (3 citations)
- Poor Nursing Care (16 citations)
- Poor Personal Care (5 citations)
- Disrespect for Caregiver from Physician, Social Worker, Nurse, other HCP (12 citations)

Of these 15 categories, 4 can be disregarded because of the small number of citations related to them: Not Meeting Caregiver's Expectations for Treatment, Poor Health Care Facilities, Quick-to-Diagnose HCP, and Poor Personal Care. This leaves 11 to be covered in this chapter.

Nine of the 40 caregivers experienced the most serious episodes of negative medical interaction. Those nine caregivers also expressed the majority of the citations for the categories listed above, with the exception of Early Disregard for Caregiver's Concerns by Physician and Lack of Support from Physician or other HCP. Thus, this chapter will begin with the two more generic issues about negative medical interactions and then focus on the 9 caregivers who experienced the greater intensity of those interactions.

Regarding generic concerns, there are two demographic indicators for negative interactions revealed in this research, the first of which is age cohort. Those 7 caregivers out of the original 40 who were over 80 years of age expressed only 10 citations for negative medical interactions. Yet of the three caregivers in their fifties, there were 30 negative medical interactions. There are no 80+ year old caregivers in the group of 9 who expressed many negative medical interactions. All three of the 50-59 year old caregivers in the sample of 40 are included in the group of 9.

This cohort effect, predicted by Carpenter and Dave (2004), regarding interactions between caregivers and physicians, is especially relevant referring to caregivers in the future. Increasingly, younger cohorts of spousal caregivers will bring different expectations into their medical interactions and leave with different reactions.

The other demographic indicator for negative interactions was gender. Men made up 11 out of the 40 cases or 28%, yet only accounted for 15% of the negative medical interactions. Furthermore, in the group of 9 caregivers with the most negative medical interactions, there is only one male, or 11% of that sample. Women made up 29 of the original 40 cases, or 72% of the sample, but 89% of the worst case negative medical interactions.

What this suggests is that, as the number of spousal caregivers increases, and younger cohorts of more assertive, educated women find themselves in that role, the percentage of negative medical interactions also may rise. This added stress for the caregiver works against the social model of aging-at-home, with informal, family caregiving sustaining the dementia spouse for as long as possible.

Perhaps examining the specific cases of serious negative medical interaction will point out not only the causes of this damaging stress, but also suggest possible interventions that might be more sustaining to the spousal caregiving model of long term care, or aging-at-home.

Types of Stressful Medical Interactions for Caregiver

1. Early Disregard for Caregiver's Concerns by Physician

Twelve caregivers, 30% of the respondents, reported a problem with their primary care physician regarding the initial assessment of their spouse's condition. The typical scenario for these 12 caregivers is that the physician would do the annual physical, listen to the caregiver's concerns, and then disregard him or her, as in Moira's (I-6) case:

> . . . In fact I had taken him to, four years ago, I took him to our internist, and he was very patronizing. Patted me on the head, and said, "Well, it is age-related." I said, "You got through taking care of my father till he was 94. And my father never behaved this way. And never had some of these crazy episodes." "No, no, it is age related."

Karen (I-2) was told, "Have him do a crossword puzzle every day." Grace (I-38) took her spouse to their HMO, and because he was "good with the president, the numbers, the questions they asked," Alzheimer's was ruled out, and she was told not to worry. "But I knew something was coming."

When Jill (I-31), after 58 years of living with her spouse, brought her concerns to her physician, she was told that he was fine, and that Jill wouldn't want to put him through the tests. It took another year of decline, before Jill brought it up again, and asked for testing.

These stalling patterns not only prevent the dementia spouse from being treated with the appropriate early medications, but they call into question the caregiver spouse's sense of his or her partner's mental status. Instead of really listening to the caregiver spouse's litany of observations, the physician may rely on something called the "mini-mental exam," a controversial diagnostic tool, formally known as the Mini-Mental State Examination, MMSE, developed in 1975. Although this easy-to-administer test has been proven to reveal moderate to severe dementia, it is not a good predictor for early, mild cognitive changes (Rosack, J., 2006). Still, this MMSE may be administered and then will outweigh all of the spousal reports, creating poor communication between the caregiver and the physician.

2. Neurologist Lack of Rapport with Caregiver

Following the initial medical encounter with the primary care physician, what usually follows, if not the first year, then the next year, is a referral to a neurologist. Nine caregivers expressed a negative experience with a neurologist, and in most cases, it had more to do with the tone of the interaction. For example, Moira, as shown above, was told her husband's behaviors were just normal aging, but she demanded to see a neurologist. When she finally did see one, the opening comment from the neurologist was, "Why isn't he on Arricept?" This brusque accusatory salvo was well met by Moira, who responded, "Call your colleague. I asked for it."

Another caregiver, one of the husbands, describes his neurologist this way, "He's a jerk. I don't know what's wrong with him . . . but just ignore it because that's just his personality." Another male caregiver, Doug (I-18) says the neurologist tells him that his wife has to walk. Doug believes in fitness, and has even installed a fitness room in his condominium, where the dining room would be, but also knows the reality of the dementia. He cannot force her to walk. He tries, but what good is the advice if the disease gets in its way? Although the men in general are not as upset by these medical interactions, they seem to save most of their critical comments for the neurologists. Dan (I-29) describes his wife's first neurologist as a "wise guy."

Sue (I-32) says she was given the name of a group and chose the neurologist just because she recognized the name. "I didn't know where to go; I didn't know who to ask; I really wasn't familiar." Although she thinks her husband's neurologist is all right, she describes him as "cold" and says, "He's good but he doesn't offer information." Since neurologists have an important role to play in the diagnosis and treatment of the dementias, the fact that so many of them are not liked by patients and caregivers suggests that they may want to look at their office structure. If they, themselves, do not have the time or personality to work patiently with dementia caregivers and spouses, then perhaps they could make up for their own insufficiencies by making sure that they have a supportive office staff.

3. Office Staff Communication

Everyone has had both good and bad experiences with their physician's office staff. However, the dementia caregiver spouse needs a supportive office staff, especially if the physician doesn't have much time for the couple. There weren't a high number of negative interactions with office staff, but each one is very unsettling for the caregiver. Sometimes it is a simple matter of trying to get a callback, or an appointment, which may never happen. One case involved a billing problem, caused by office staff, which led to a letter writing campaign by the caregiver until it was resolved.

The worst examples showed actual disrespect for the caregiver, as in the case of Maggie (I-11). Maggie also was given the name of a neurology group, but in her first visit, did not like the physician. Then, her friend, also with a dementia spouse, tells her that she should have asked for the other physician in the group. When it is time for her spouse to see this group again, she asks for the "recommended" doctor. However, the staff person tells her that she saw the other physician, and should see him again. When Maggie pushes, they want to know why. This leads to her rather forceful response, "Because I am the patient. I can change my mind. I don't even have to come to you. Don't ask me why."

4. Lack of Cooperation from Physicians or Staff

This follows from the negative interaction just above. Sometimes, the caregiver needs the support of the physician or staff and doesn't get it. This is a wide ranging category, but generally relates to stressful situations made worse by the physician or staff because they do not follow through with calling back, sending reports, providing information, etc. For example, if the physician is giving the caregiver and dementia spouse a diagnosis of dementia, the couple has many questions and are emotionally stressed. To answer their questions about the dementia by referring them to the Alzheimer's Association, is perceived as "blowing them off." One might compare it to the prospect of getting a cancer diagnosis, and being told to take one's questions to the

American Cancer Society. When this happened to Sue, she said she was surprised because she thought she might get information from the doctor.

Again, even if the physician doesn't have time, it would be supportive at such a devastating moment, to have a nurse who could speak to the couple in a very general way about the support resources that exist in the community. Even being able to pass on pamphlets of information would be helpful. These are difficult times, made more difficult by the lack of sensitivity and information from the health care providers.

5. Incomplete Information from Physician or other HCP

During the course of dementia, patients can have bad episodes, where there is a sudden dramatic loss of ability and function. Sometimes, these are of short duration and resolve themselves as care is administered, but sometimes, there are lasting effects. For many of the caregivers, these episodes are total mysteries because of the lack of complete information from health care providers. Louise's husband had emergency hip surgery and was hospitalized. That hospitalization marked a significant loss of ability, especially conversational ability. "When I brought him home . . . he was an entirely different person. When he went … he was taking care of himself." Louise is asked if the doctors gave her any explanation for this. She responds: "No, (they say) it is part of the disease."

Some caregivers are accepting of these generic responses, but others know they are getting shortchanged. Betty (I-23) began seeing major changes in her spouse.

> Then he was sitting in the living room one night and he says to me, "Betty, I've got to go to the bathroom." I say, "Ok, get up and go to the bathroom." Because at this point I didn't see anything else. Well, it looks like he didn't get up in time. He wet himself and he fell on the floor. "Oh my god, what's wrong with you?" He said, "I don't know. I feel so weak." Right away I called the paramedics. They were there in about 5 minutes. They took him to emergency and . . . they examined him good and everything and . . . the doctor, Dr. G., I think, he says to me, "Mrs. M., I suggest you sell your house as soon as you can."

The physician goes on to say that her spouse can't work any longer, but doesn't actually tell Betty what is wrong. She remembers hearing the word "dementia." Besides telling her to sell her house, ". . . it's like he couldn't really tell me much else."

The examples grow more and more bizarre. Maggie (I-11) brings her spouse home from the hospital, and sets up home care, but the doctor never told her that her spouse was non-ambulatory. What he did say was: “He shouldn’t have any problem walking.” While in the car, her spouse tells her that he can’t walk, and so they stop along the way to pick up a wheelchair.

6. Medication Issues

If there is one topic that stirs up confusion for the caregiver, it is the topic of medications. Ten of the 40 caregivers had negative medical interactions related to medications. Not only do they have to watch their dementia spouse carefully in regard to the medications, but they take medications themselves. Doug (I-18) speaks of the prescriptions he is supposed to take: “The sad part about things . . . back in the old days it was better. You got sick, you died. This way here the doctors are practicing on you. This clown I go to, all he thinks about is pills. This isn’t right-- take another pill. I keep telling the guy I don’t like taking pills. He says, ‘You got (sic) a situation home where you got to take care of yourself. You don’t want to see anything happen to yourself.’”

The medications for dementia are numerous, and there is a pattern of “try this one, and if it doesn’t work, we’ll try that one.” There are also stage-specific medications. The well spouses hear about the options on television, but more importantly, in their support groups. What one spouse will tolerate and respond to, another will have a bad reaction to. Besides the dementia-oriented medications, most of the dementia spouses also take some kind of psychotropic medication to counteract their depression or anxiety. These medications often do help with controlling difficult behaviors, which is the idea, but it takes time and experimentation before the physician knows whether the patient will benefit from the medication. This is why the caregiver spouses often see the physicians as experimenting with their spouses. They don’t trust them.

There is an additional issue regarding the medication of dementia patients. Sometimes the drugs are quite numerous, and there is a common belief among many health care professionals that less is better. In general, that would be true, but some of these patients have highly sophisticated diagnoses, multiple conditions, and indeed need the medications they are on. When the spouse goes into a hospital or long term care facility, or even medical model adult day care, medication challenges rise to the surface, endangering the welfare of the dementia patient, and thoroughly frustrating the spousal caregiver, who typically manages the medications at home.

One example is Brenda (I-8). When her husband has a stroke at home, one of the episodes referred to above, and is taken by ambulance to the hospital, Brenda is asked about his medications at each point of contact. The ambulance crew asks her; the hospital asks her; and ultimately, the rehabilitation center asks her. She suspects that they probably reduced his medications in the hospital, to make sure the medications weren't causing the problem. While he is at the rehabilitation center, she visits him regularly.

> So anyway, I would go twice a day, and I would wait until they put him into bed, and they would always put me out of the room, when they were getting him ready for bed. And so then, they got him in bed, and when I came back in, another lady comes, and she starts to talk to him. I said, "Don't talk to him. Talk to me. He don't (sic) know what you are talking about. He can't hear you, he don't know what you are saying." So she says, "Well, we see blood. He is bleeding." I knew that was going to happen. Cause that day was the first day I actually saw them giving him one pill. . . The colitis! At that time he was taking 8 (*pills*). . . and he has been taking it forever. And they were breaking him down to maybe one or two a day. I said, "I knew this was going to happen."

In another story, Kieran (I-36) talks about how he and his daughters decided to have his spouse admitted to a psychiatric facility in order to adjust her medications. "The other thing is most of the doctors say that they can't be proactive with the medicines as far as bringing the strengths up unless she's admitted to a hospital environment. We did that. . . We brought her over to *ABC Psychiatric Hospital* and they just mega-dosed her … to the point where she wasn't speaking, she wasn't walking, (she was) falling down." Since that hospitalization, his wife no longer speaks, and has many more anxious behaviors.

Thus, it is easy to see how medications can be a sore spot for physicians and caregivers, not to mention the individual dementia spouse who takes the medications. Bella (I-37) has had many negative interactions with the health professionals in the adult day care centers and nursing facilities where her spouse is cared for. He is one of those cases on a very sophisticated round of medications, in order to control pain. Despite the fact that the medications were ordered by reputable physicians to help this unusual dementia patient, a younger man (65) who has had the dementia for 11 diagnosed years, Bella has found numerous times when the staff of various facilities reduces the medications on their own, usually leading to a hospitalization of the spouse. After it happened several times, she developed a theory:

> At *XYZ Nursing Home*, they would let me take him to his pain specialist and his neurologist and they would write orders and they did abide by them for a long time and all of a sudden … I'll tell you exactly what starts it. It's the pharmacology reviews … they go through these reviews and the state says this patient is on far too many medications … you have to take them off.

These are diverse examples of the wide range of complications that medications can make for all parties involved. There aren't any easy remedies for these problems, but physicians and caregivers alike need to be aware of them.

7. Underestimating Dementia Effects

Health care professionals (HCPs) have a tendency to underestimate the effects of the dementia on the communication skills of the dementia patient. This leads to negative medical interactions because the spousal caregiver is often overlooked as the more likely candidate for giving answers. Recall the case of Brenda, above, whose husband was bleeding, and the nurse questions him rather than her, causing her to somewhat angrily respond, "Talk to me." These are the days of HIPAA rules, so HCPs are somewhat pushed in this direction, to try to confine the communication between the dementia patient and the HCP. Furthermore, no one wants to be accused of treating the dementia patient with disrespect. Still, when they cannot communicate, as seen in Brenda's example above, it is bizarre not to go to the spouse for assistance.

When Lawrence (I-14) is told to bring a urine specimen from his spouse, he asks how to do it. His wife is almost non-responsive and cannot simply be told to urinate into a cup. "You can't collect urine. In the morning when she has to give urine, I take the pad and I squeeze it into a container. That's the only way to get urine. They have all sorts of gimmicks. They say you do this or do that. I say I can't. They don't seem to realize that this woman can't stand, she can't respond to a request …" The physician who told Doug (I-18), that he needed to get his wife walking, was underestimating that kind of task. Doug wants her to walk, but she just won't anymore.

Dina (I-15) has a dementia spouse who also suffers from PTSD. He sees a psychologist, and tells Dina that the psychologist wants him to get a PDA (Personal Digital Assistant), so that he can record things on the PDA and remember better. Dina just laughs. "So I'm thinking, how is that going to help? How is this going to help? He could write things down on a piece of paper and he doesn't do it."

Although these examples are not likely to harm the patient, there is a basic concept here that needs to be taken seriously. Dementia spouses often cannot articulate for themselves, and spousal caregivers should always try to be in the room during medical interactions.

8. Lack of Support from Physician and other HCPs

Lucille (I-35) is an 82-year-old caregiver, for her husband who has been diagnosed with dementia for 6 years. She shared some of her feelings about physicians.

> He's alright. We belong to a plan. It's the same with all doctors nowadays. They really don't have too much time for you. You're in and you're out in 10-15 minutes. . . I'm used to the old time doctors that took time with you and today the whole system has changed. . . you sit down and get the feeling they're anxious for you to leave . . . I go way back. I remember when you paid $2 to see the doctor . . . $3 if he came to the house and he'd be with you an hour if necessary. You can't expect that today but . . .

Still, Lucille believes that her spouse's doctor treats her husband well. When Lawrence, an 85-year-old caregiver, is asked if he gets support from his physician, he says, ". . . not really. We were friendly with each other. It's nothing that I took umbrage of. It's just the way it is."

Christina (I-27) has mostly positive things to say about her medical interactions, yet did have one bad moment, when a female physician wanted to hospitalize her dementia spouse for three weeks in order to treat a possible case of lyme disease. "I'm like no way.

He's having major cognitive (problems) and I know what that does in the hospital. She was very … I didn't like her at all. She was just not caring … cold." She sees the physician as uncaring, but the physician is not looking at the situation with the eyes of a spousal caregiver. She wants to treat the lyme disease, and is not considering the possible cognitive side effects of a hospitalization. Yet time after time, the interviews showed cases where the dementia spouse has almost psychotic reactions to the hospital setting. A hospitalization of a dementia patient almost always causes more downward momentum. Surgeries can cause even more damage.

In a more desperate case, Kieran (I-36) is trying to get his spouse into a facility. He has visited an assisted living facility, the kind of place he thinks may be good for his spouse. Essentially, he is testing the water. Over the phone, the facility is supportive, but when he shows up with his spouse for a tour, things change.

> The girl that was supposed to give us the tour was giving another tour. I called ahead but their phones were down. I went there anyway and the Director gave us the tour. He was looking at it as an administrator or maybe with a liability point of view … having somebody like D. *(56 years old)* with all these older people. She was starting to act up while she was there and he saw that. First they were talking to us telling us all the positive things about the place and then the conversation turned to, "Well right now our capacity is full." I know I got (sic) the bad kid in the class. I'm working very hard to get her medication adjusted. He said, "When you get that done, we'll do an evaluation."

This perceived lack of support from health care providers, on the part of the caregiver, weakens the caregiver. Lawrence may not "take umbrage" over it, but instead of having a trusted partner to help the caregiver with the challenges as they come, he or she feels even more alone.

9. Poor Nursing Care

Unfortunately, the bottom line regarding nursing homes, hospitals, and rehabilitation centers is how well the patient is cared for, and some of these facilities come up sorely lacking. Why would so many people try so hard to stay out of those facilities? The interviews showed 16 negative medical interactions reflecting poor nursing care, but these were all from five cases. It should be remembered that most of the care receivers were still at home, and had not yet experienced nursing care in a facility.

Sometimes, the cause of the poor nursing care is just the lack of staff as Grace (I-38) saw at her spouse's facility. She visits him almost daily and mostly has positive things to say about the facility, but at the same time alludes to short staffing issues. Similarly, Brenda's (I-8) twice daily visits while her husband was in the rehabilitation center, pointed up some weaknesses in his care. When he stands up to follow his family home after a visit, the nurses are shocked. They didn't know he could walk. Ironically, despite it being a rehabilitation center, he has been restrained most of the time he was there.

One of the caregivers had to become an expert overnight on nursing facilities. Annalise (I-20) had spent all of her efforts trying to care for her 280 lb. husband at home, but finally she could no longer get him up after he fell, so she had to call an ambulance and get him to a hospital. She was satisfied with the hospital care of her spouse, but the hospital had to quickly move him to a rehabilitation center. The physician told her he would give her a list of centers and she could visit them and decide which one. But her HMO wouldn't continue to cover him, and the next day, she got a call, saying he was discharged. The discharge planning person told her there was only one place that would take him, *ABC Nursing Home*. Annalise demanded that he stay in the hospital one more day, for which she will have to pay, and the following day, Thursday, he is moved to the rehabilitation center.

> I never visited there before but I had very weird feelings. When we arrived it was a typical old fashioned facility. Looking around I saw the nurse was running with some sort of oxygen ventilator device. They put my husband in a baby sized bed and he being a big man. This bed was from the last century. I saw similar beds, hand cranking. It's not an electric bed. No nothing. My husband was prone to get decubitus. He was a big man and he had to be in that bed? It broke my heart. I looked around and they plugged him in with the oxygen. That plugged-in dust field ventilator device was as noisy as a generator. I'm not exaggerating. Looking at the machine, it's old, filthy and dusty, everything. Here we go. I said, my God we go from acute care to semi-acute care but where is the rehab portion?

But this was just the beginning of Annalise's torments. On Friday, she had to go to work, but she visited again on Friday night and Saturday. Saturday, she asked if he could have a shower, but was told that he wasn't scheduled till Monday. On Sunday, the whole family visited and the spouse seemed all right, just sleepy. Monday came, and Annalise met with the social worker. This professional approves all of Annalise's requests, such as a larger bed, pureed food, physical therapy. But when she returns to her husband's room, she finds that her husband has been moved, and is greatly changed, physically.

> When I saw my husband I was very much shocked in the way that his eyes were closed and he looked sad and he was sweating and he would not talk. I said, " J., I'm here, say hello to me, give me a kiss." He didn't say anything. He just kept his eyes closed. I asked the aide who passed by, "Did my husband have lunch?" She didn't say anything. She stood around. The lunch truck was already going back to the kitchen and then she was bringing my husband's tray, his name was on the tray, untouched and started to feed my husband.

Almost immediately, her husband started choking, so Annalise ran to the nursing station and asked for help. However, the nurse did not go with her back to the room, nor did she summon a physician, as Annalise requested. Dietary has sent up a pureed tray by this time for her husband, but he won't eat. Now Annalise was very worried, and went to the nurse administrator. Her response was that he is a new patient and no one was familiar yet with his care. Remember, this was Monday, and he was admitted on Thursday night. After checking his records, the administrator offered to summon an ambulance to take him back to the hospital. Since no one at the care center will address his needs, Annalise agreed to a return hospital trip.

> The hospital cleaned him up and put him 24 hours in emergency care, and then x-rayed him … found aspiration pneumonia in the left lung. My husband, the first day he was put on IV and I felt he was feeling consciously … he was resting his hand over mine. He eyes were closed. He could not talk because he had oxygen in his mouth or whatever again. They also in the meantime had a brain scan again and found that a dilated vein (was) pressing against the brain stem. They did not see any sign of stroke so I still … I knew he had pneumonia because they told me, the HIP doctor, Dr. J. , ordered medication to reduce the fever, my husband started to escalate the fever and by the end of the 24 hours he was transferred to CCU. He had a private room and I have to say he had excellent care there.

Her husband eventually died in the hospital, and was not subjected to any more time in a rehabilitation center. Obviously, Annalise's story is from her perspective only, but even if exaggerated, it is clear that, nursing care was not at the caregiver's expected standard.

10. Poor Medical Care

Ten caregivers reported episodes of poor medical care. Millie (I-13) generally was positive about her physicians, but did change primary care doctors for her husband, because the first one never even took his blood pressure. Earl (I-16) was frustrated by the lack of information from doctors, "Even my own doctor doesn't even know. If I say I want "x" prescription. Ok, here. They don't know. The only reason I go there is they take blood tests and stuff like that." Most of the couples try several different physicians when trying to get a diagnosis. Like Doug (I-18), many feel that physicians are afraid to give a diagnosis. "You go from one to the next to the next and nobody wants to say a diagnosis because something's wrong down the line you turn around and sue 'em. This is the game that everybody plays so you get that circle that you're in with the medical profession, it's the same stuff."

The worst case of medical mayhem was Martha's (I-33) situation, caring for her dementia spouse for 15 years, 8 of them spent trying to get a diagnosis.

> Dementia is a weird illness in as much as when it starts to manifest itself nobody knows what it is, nobody knows how to deal with it … he was diagnosed as a sociopath. There's a lot of weird things that happened in between and … we just thought he was a nutsy man. At that time, he was going to the veterans' out-patient because the therapist we'd been seeing supposedly for marital counseling couldn't do anything with him.

This is Martha's second husband, the first having died in an automobile accident, leaving her with two small children to raise. She and her dementia spouse had one child together, who also died, during the spouse's early years of dementia, again in a violent car crash on his way home from his college in Pennsylvania. Martha is no weakling. She tries as well as she can to cope with the bizarre behaviors, but it leads to many arguments. He almost bankrupts them due to declining cognitive ability. Still, she has no correct diagnosis. She is counseled to leave him. Yet she loves him. Finally, the psychiatrist she is seeing, to help her cope with her own depression, following her son's death, tells her to go to *Famous Hospital* for a complete workup.

> He had a complete work up but they wouldn't give him an MRI and the doctor patted me on the shoulder and said, there's something wrong with him. It's like a plug in a socket and it's not connecting but I don't know what it is. They sent me to a social worker who told me to lay off of him because it sounds like Munchausen's by Proxy . . .

Now, still without a diagnosis, the tables are turned, and Martha is accused of fabricating her husband's illness for attention (Munchausen's by Proxy), by a social worker no less. When Martha returns to her referring psychiatrist, she suggests that she keep a journal of all of the behaviors, day by day, and then ask for another screening. The local veteran's facility agrees to do another assessment, after reading the journal. This time, even the verbal tests showed that something was wrong with frontal lobe activity. Finally, they administer an MRI, the one test no one would give him earlier, and discovered, "the whole frontal lobe of his brain was totally atrophied." Finally, after 8 years of searching, Martha and her spouse had a diagnosis, and could begin treatment.

This is one of the problems with the dementias. There are many causes, so that if the spouse doesn't present with the expected Alzheimer's symptoms, it is sometimes difficult to pin down the disease. As one of the HCPs at the veteran's facility said to Martha, "I can't believe this, I looked at all his past records and I said why don't you listen to the patients' families?" Martha says, "Why don't you listen and stop being so clinical and maybe you'll learn a lesson that'll open up your mind because when I spoke to the other person, she told me that I was crazy … that I don't know what I'm talking about. I'm the one that lives with him."

11. Disrespect for Caregiver from Physician, Social Worker, Nurse, other HCP

Martha's example leads to this last category, because more than any other interviewed caregiver, Martha was faced with disrespect for eight years, mainly because the medical world could not discover what was really wrong with her husband. Finally, all they could do was blame her. Munchausen's by Proxy. She was the cause.

Bella (I-37) had a similar experience, and again her spouse has a rare form of dementia, and experienced it while young. Both of these dementia spouses were often charming to their medical caregivers, and aroused empathy from them. Surely this younger man can't have what all these old people have. The wife must be conspiring to make him crazy. Perhaps there *are* cases where wives and husbands conspire to get rid of their spouses, but in this research, there was only pain and agony for these spousal caregivers, who can only really ask, "Why me?"

Still they provide care for many years in increasingly difficult circumstances while raising children, and working to keep an income for the family. In neither case was there any financial advantage to the search for a diagnosis. But there were definite reasons to keep looking.

Do more typical dementia couples encounter the same disrespect? Most of the people interviewed did not speak directly of disrespect. Some did not feel supported by their HCPs, as shown previously, but did not offer stories of conflict like Martha and Bella.

However, one caregiver, Judith (I-9) is an example of a caregiver in a normal dementia experience who did encounter disrespect from her HCPs. She had been a caregiver for ten years for her dementia spouse who is 77. She is 72, and still working. Judith is also the caregiver who has supportive adult children, one of whom lived in the same house as the couple, along with her husband and son.

Judith's spouse has a cardiologist and internist but tends to not see him, and instead sees the physician's assistant. Judith leaves a phone message for the physician because she is very concerned about her husband. No one ever calls back. Finally, she goes to the office and makes an appointment. However, the physician tells her spouse that he probably has arthritis of the neck. Judith immediately addresses the physician and says that these are not normal headache pains. The physician responds, "Well, are we a doctor?" Now she asks for a CT scan or an MRI. Then the physician refers her to a neurologist.

When they see the female neurologist, she has them wait while she is on the phone. When she finally addresses them, she says, "Dr. J. tells me your wife wants you to have an MRI. Do you want one?" "I, uh." She (the physician) says, "That's it. We don't need one."

Needless to say, Judith did not keep that appointment, but left with her husband. Later, she and her daughter return to the original doctor's office, and see the physician/spouse of the first doctor.

> She didn't want to talk to me. She said, "I can't talk to you without G. *(the dementia spouse)* being here." And my daughter was with me. So I said, "Don't talk, listen. This is what is going on." So she said, "You switch from my husband to me. You make an appointment, and bring G. with you, and we will talk about this in front of him." And that is what we did.

The strange behaviors continued, including some scary moments behind the wheel of their car, so Judith's administrative assistant tells her about the dementia clinic at *Big Hospital.* Judith makes an appointment and asks her spouse's doctors to send the records. They do not. So she drives back to the doctor's office and asks the nurse for the records. "'You never faxed any of the information.' She said, 'We will do it now.' I said, 'No, no no. Give it to me.' I said, 'I will take them. I am going to my office and I will fax them.' So that is what we did."

A few days later, she asks the office to turn over all the records to another doctor. The office staff tells her that it is too big to turn over, so she should come pick it up. Judith sends her daughter, P., who is in the area. "They made her wait one hour , . . P. said they were so rude. And then they said. 'Well, I see your mother is still in charge!' And she (P.) said, 'She damn well is, and thank god she is.'"

The problem with all of this game playing is that the spouse's dementia is not really being treated. ". . . and I honestly think if Dr. W. had addressed this six years ago, we would have been so much better off." Then, her husband needs prostate surgery, and she asks that they give him spinal anesthesia, to avoid the risk of anesthesia related brain damage. "They didn't. They must have given him regular anesthesia. It took five weeks for him to be able to walk again. So, that's when the trouble started, from that point on. He was falling a lot."

It is easy to feel Judith's frustration with the physicians. Later in her story, there is a home care incident where the nursing care isn't correct, and her spouse ends up in the hospital, dehydrated. This really brings on the crisis point, or tipping point. Despite all of the supports in place, adult day care, home care, adult children assisting, Judith's spouse needs 24 hour nursing care. But like so many symbiotic couples, Judith doesn't want to give up. Finally, she seems to have a physician who respects her role as caregiver. The physician says, "'He's here (the hospital) and he is not going home again." (Judith whispers this during the interview.) She said, 'It's time.' She had been watching him carefully. So, that is when we made the decision."   The physician makes the decision for Judith and her family. It is the right decision, because otherwise, Judith and her spouse would have become a toxic couple. Already, the whole experience had taken a heavy toll on the whole family.

Judith's story is just one of the many in this study where the interactions with the medical practitioners added great stress to an already stressful situation. By trying to tease out the specific reasons for the stress, it is clear that there are alternatives to these scenarios, some of which will be suggested in the Conclusions and Recommendations covered in Chapter 7. This chapter suggested ten precipitating factors for the stressful interactions, but there are likely more. Why isn't this topic studied more by those trying to address problems of burden in spousal caregiving? Although not addressed in this chapter, it is likely that adult children may also get caught in these stressful interactions, especially since many of them are younger and female, reflecting the very categories of age cohort and gender that express the most difficulty with medical professionals. What has been uncovered with spousal dementia caregivers has the potential for defining a majority of future medical interactions between caregivers and physicians, since the numbers of female caregivers in the younger cohorts, the baby boomers, are growing into the spousal caregivers of the future.

Thus, medical interactions have the potential for either great support and mediation, as just shown in Judith's final interaction with a physician who helps her resolve her conflicted feelings over institutionalization, or for great stress, and ultimate harm to the caregiver, as shown by everything else in this chapter.

CHAPTER VII: CONCLUSIONS AND DISCUSSION WITH IMPLICATIONS FOR POLICY AND PRACTICE

By interviewing forty spousal caregivers for persons with a perceived cognitive deficit, it became clear that the spousal relationship itself not only sustains the care receiver, but affects the caregiver in both positive and negative ways. Since it wasn't possible to limit respondents to those just in the middle stage of caregiving, at the moment when they were just starting to assist with an Activity of Daily Living (ADL), the original research question had to be expanded. That question (p. 3) concerned high levels of perceived burden in that middle stage of dementia caregiving, as expressed by spousal dementia caregivers in the study by Farberman et al. (2003). By expanding the pool of spousal dementia caregivers to include those in later stages as well, not only was that question addressed, but also imbedded into a broader perspective of caregiving, one that followed the couple throughout the dementia journey.

The grounded theory arising from this research points out that the relationship intensifies and turns inward during the caregiving experience, thus clarifying **why** spousal caregivers often become overwhelmed by various sources of stress and burden, and **when** intervening mediators should be attempted to support both care receiver and caregiver.

The Metaphor of Symbiosis Applied to a Stage Theory

Using the metaphor of symbiosis, the data from the interviews pushed in the direction of a stage theory, and indeed all of the caregiving couples in the sample of 40, with one exception, were moving through the proposed stages, based on types of biological symbiosis, with most in the commensal stage where the care receiver was indeed dependent on the caregiver, but not yet seriously detracting from the caregiver's physical or mental health. This empirically grounded stage theory, including transitional events, is supported by similar approaches toward understanding the caregiving career (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Gaugler, Zarit, & Pearlin,2003;

Kosloski & Montgomery, 2000; Gaugler, Zarit, & Pearlin, 2003). However, it differs from previous attempts because it frames the conceptual model in terms of the dementia couple's social identity.

Furthermore, although Kosloski and Montgomery included seven stages, mostly tied to marker events in the process, they still relied on the structure that ends in institutionalization and the ultimate death of either the caregiver or care receiver. Seltzer and Li (2000), and Gaugler et al. (2007) used the three stage structure referred to most commonly in the caregiving literature: 1) Entry into Caregiver Role 2) Institutionalization 3) Bereavement. Burton et al. (2003) completed a longitudinal study that specifically looked at transitions during spousal caregiving, but still used the three stage model. The negative connotations in the last two stages of these theories tend to emphasize the pessimistic view of caregiving. By contrast, the empirically grounded conceptual model of a symbiotic journey in spousal caregiving concludes with two possible scenarios: a toxic dependent symbiotic relationship, or a mediated dependent symbiotic relationship. Institutionalization becomes one more mediator that prevents the relationship from becoming toxic.

This important difference from the other models should have positive application in the field of supportive services for dementia caregivers. Since the research is limited to spousal caregivers, it would not apply universally to all caregivers, but it should help social workers and care managers guide spouses and their adult children in the decision-making process for **when** to bring in supportive services. As with all stage theories, this theory not only reassures the caregiver that his or her feelings and stresses are normal, but also points out the value of the mediating services which become necessary at strategic points in order to prevent toxicity.

Focusing on the couple in the stage theory design, rather than on the caregiver alone, reflects the emphasis of the design of this study; that is, limiting subjects to spousal caregivers. The notion of a caregiving "dyad" has grown stronger in the research literature, as suggested by Lyons, Zarit, Sayer, and Whitlach (2002); Whitlach, Judge, Zarit, and Femia (2006). Although the interviews were conducted only with the spousal caregiver, the care receiver, by virtue of the theory, is intimately bound up and dependent on the caregiver. In addition, the more serious effects of caregiving, those involving deteriorating physical and mental health, more frequently show up in spousal caregiving (Alspaugh,Stephens, Townsend, Zarit, & Greene, 1999; Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998; Powers, Gallagher-Thompson, & Kraemer, 2002). The potential toxic stage in the symbiotic framework reveals those forces that may lead to poor physical or mental health, especially depression.

The relevance of looking at the issue of caregiving from a spousal perspective is further validated in the literature that uses a “strengths” approach to the challenges presented by caregiving. Spousal caregivers have a lifetime of experience with the care receiver to use as a basis for not only finding meaning in their new role and identity, but also for maintaining their commitment (Lewis, 1998). Long before the dyadic concept was being written about in caregiving research, Kramer (1993) stressed the importance of using a relationship-focused approach not only to evaluate the stress for the couple, but also to tap into coping mechanisms. Relationship-focused coping aims at enhancing or preserving relationships, but also could mean disrupting relationships. For the symbiotic couple, both preserving relationships and disrupting relationships are addressed, through the mediators listed in Stage 5-B. The engagement of the supportive adult children, the recommendation to join a spousal support group, to use adult day services, or to bring in home care, all support the relationship, and hopefully, prevent toxicity. However, the recommendation to place a dementia spouse in a long term care setting will disrupt the relationship, again, as a final measure against toxicity.

Social Identity, Symbolic Interaction, and Dementia Couples

The majority of research on caregiving, especially dementia caregiving, emphasizes burden, as initially developed by Zarit (1980). The Zarit burden scale is ubiquitous in the caregiving literature, but it does tend to emphasize all of the negative aspects of caregiving. Indeed, it was this scale in its shortened version (Bedard, Molloy, Squire, DuBois, Lever & O’Donnell, 2001; O’Rourke & Tuokko, 2003), that provided the basis for the data leading to the current study. Farberman et al. (2003) showed that burden was at its highest in the mid-stages of caregiving, and strongest for spousal caregivers.

Chappell and Reid (2002) give a good summary of the many meanings for burden in the literature, and, in the current study, burden somewhat equates to the qualitative code, “caregiver stress,” which appeared 1,436 times in the forty interviews, making it the most frequently cited code. It is no wonder that so many researchers wish to study burden in caregivers, and burden or stress in spousal caregivers is the dominant psychological state perceived in the current investigation. However, it is only one portal for understanding the caregiving experience. The grounded theory of symbiosis goes behind the stress, not only to describe the **identity transition** that may be contributing to the stress, but also to explore which source of mediation works the best for the symbiotic couple.

What is this identity transition in symbiosis? There are actually two kinds of identity operating in the symbiotic theory: individual identity and couple identity. From the beginning, social identity theory and symbolic interaction seemed to relate well to the problem of the spousal caregiver in mid-stage caregiving. It is the symbolic interaction theory, rooted in Cooley’s “looking-glass self” and Mead’s “interaction”, that gives us Blumer’s concept of the individual’s engagement with society, facing up to what, in this case, the dementia caregiving experience is presenting. The caregiver’s social identity is changing as the care receiver’s new behaviors and communications change the interaction between them, and ultimately lead the caregiver to revise his or her conceptual belief about the relationship and about himself or herself. It is approximately in the middle of the dementia caregiving experience, when the caregiver must assist with an ADL, that his or her identity is most sorely challenged, leading to high stress. This is the stress of a transitional period, when roles are very confused, and thus helps to explain the findings of Farberman et al. (2003).

During the interviews, notions of a changing perception of self identity were common. Some saw themselves becoming stronger, more decisive as their partners lost ground, and others saw themselves becoming more antagonistic, more petty. Many questioned what was happening to their own identity, while experiencing the significant change in their dementia spouse’s identity. These are changes in individual identity caused by interaction with the spouse. But the caregiver also interacts with many others while in the company of the dementia spouse. As stated earlier in the introduction to the paper, the caregiver can be validated through social interaction, but can also be shunned through the withdrawal of other social interaction. Goffman's concept of stigma is common throughout the interviews and is a contributing factor to why the caregiver spouse starts to limit social engagements. This action not only spares the dementia spouse from feelings of confusion and alienation, but also spares the caregiver from stigma by marital association. Furthermore, as shown by Deutsch and Krause (1965), the couple is really a "deviant" couple. People with dementia no longer live up to social norms or expectations, so they are not only covered in stigma, but also viewed as deviant from what should be expected from the role as an elder in society.

Also related to this concept of a stigmatized identity, it makes sense that any service or intervention that fails to consider this role of stigma and deviancy is doomed to failure. Perhaps this answers the universally stated query and complaint, "Why don't they use this wonderful service?" Fill in the blank with adult day care, respite care, support groups, or home care. In each of these modalities of supportive service to caregivers, depending on how the service is structured, there is an element of identity disclosure. The deviant, stigmatized couple must come forward and self-identify. They must disclose that they too are now in this "dementia-tainted group." Anyone planning senior services, must address how to get past this wall of justifiable resistance.

Continuing with the problems of identity, and referencing the work of Duck and Lea (1983), the couple has suffered losses in three areas of their couple identity: similarity, intimacy, and public identity. All three are seriously threatened, even though the spouses continue to co-reside. They are no longer as similar to each other as they were; they have very limited moments of intimacy; and their public identity is actually stigmatized. Both spouses indeed find their individual identities threatened, because they have in a sense lost part of themselves, owing to the changing nature of the relationship. Perhaps this gap in individual identity is filled by the growing symbiotic identity.

The last theorists, Stryker and Burke (2000), proposed that we have identities based on the roles we play. Stryker and Burke say that we organize these various identities into a "salience hierarchy" which is determined by the individual. These identities are cognitively-based “schemas” that help us define situations, and give us cues for how to behave (p. 286). Furthermore, “commitment shapes identity salience shapes role choice behavior” (p. 286). How does this relate to the dementia couple? First of all, commitment is at the basis of most elder married couples. Their marriages truly have stood the test of time, with many of them now approaching anniversaries of 50 and 60 years. Therefore, in the Stryker/Burke theory, identity salience would be very strong for their married identity, based on their commitment. In fact, within the interviews, even a couple with a long history of conflict, was viewed by the caregiver as a committed couple. The role choice of spouse is one that actually would lead them to vacate other roles and identities, if necessary, in order to practice the behaviors associated with their spouse role. Thus, the one caregiver in the sample who was young with a three-year-old child, did not have the commitment, because she could not vacate her parental role. Indeed, dementia caregiving requires that the well spouse abandon most other relationships in order to carry out the demands of the spousal caregiver identity. For the young caregiver, the caregiver role would be relinquished through divorce, because she could not perform both roles given the obstacles she perceived. But for all of the remaining caregivers, the spousal identity was the most salient, and was causing them to neglect other identities, such as parent, friend, and neighbor.

This narrowing of identity to “caregiver” is not perceived till somewhere further along in the caregiver passage, long after entry into the role, and long before potential institutionalization. **This may be the key realization that triggers the burden in mid-stage caregivers.** Using the symbiotic theory, this awakening probably comes post diagnosis, perhaps in the transitional period of adjustment, or just into the commensal stage. It seems to be a spousal caregiving phenomenon, for it is doubtful that the typical adult child caregiver would or could forsake all other identities, especially his or her spousal or parental identity, for the identity of the adult child caregiver to a dementia parent. Symbiosis between dementia parent and adult child is unlikely, but not impossible, if the parent and adult child were similarly isolated and committed.

Thus, the identity theories help explain the drift toward a more toxic level of symbiosis, as they underscore the effect of stigma and salience. They also suggest that the individual identity of the caregiver is being subsumed by the dementia couple identity. This shift does not appear to be healthy and certainly contributes to the tipping point, where toxicity is the result unless mediating services are put into effect.

Gender, Ethnic, Racial, and Geographic Representation

Does the empirically grounded stage theory of symbiosis hold up for all spousal dementia caregivers, regardless of gender or race? Because this was a purposive sample, looking generally at spousal caregivers of those with a perceived cognitive deficit, there was no formal attempt to insure that gender and racial representation would be addressed. However, male and African American interviewees were actively sought by the investigator, in order to provide some basis for anecdotal comparison.

Research findings in the literature are mixed concerning ethnic and racial differences in caregiving. Two studies looked at Black and White caregivers' differences. Roff, Burgio, Gitlin, Nichols, Chaplin, and Hardin (2004) found Blacks related more positive aspects of caregiving than Whites, using a sample of 273 Blacks and 343 Whites. Religiosity also was related to a more favorable appraisal of dementia caregiving. What was not significantly different was level of social support or depression. The other study (Williams, 2005) was also conducted with a large sample, and looked at depression again. This one found that Black and White caregivers did not differ significantly in the number of formal support services used, in the size of the social network, or in the number of depressive symptoms reported. Black caregivers, however, did report higher levels of received support than white caregivers.

Another major meta-analysis of ethnic and racial differences in stressors, resources and psychological issues, included Black, White, Hispanic and Asian American caregivers (Pinquart & Sorenson, 2005). Comparing the findings of 116 empirical studies, one of their key findings concerned psychological issues for the caregiver, finding that Black caregivers had less caregiver burden and depression than White caregivers, although Hispanic and Asian American caregivers had more depression than both of the other two groups.

The three non-White respondents in this study, two African Americans, and one Asian, also followed the symbiotic stages, suggesting further study within both of those populations regarding whether the stage theory holds up in a larger, more representative sample. As much as one wants to see diversity in the sample, racial diversity is very difficult to achieve in caregiver research, although there are numerous studies which have tried to address the differences, well summarized by Pinquart and Sorenson (2005).

As regards gender differences, the literature has many studies looking at these differences pertaining to caregiving. Again, Pinquart and Sorenson (2006) completed another meta-analysis of 229 studies looking at gender differences in dementia caregiving. They found that “most gender differences in stressors, social resources, and health were very small” (p. 38). However, they did find that female caregivers reported more behavior problems, more hours of care, higher number of caregiving tasks, more burden and depression, and lower physical health. Still, they reported the differences were small, and that the similarities between gender experiences with caregiving were more striking than the differences.

Yee and Schultz (2000) also found that female caregivers reported more psychiatric symptoms, such as higher levels of depression, anxiety, and lower life satisfaction. However, this difference in psychiatric symptoms may be representative of another difference between males and females, as theorized by Rose-Rego, Strauss, and Smyth (1998). Perhaps wives are more attentive to their own emotions and more likely to report negative issues such as depression, and perhaps husbands are not as likely to report their inner emotional upheaval.

This study showed no major differences in how male or female caregivers got drawn into the symbiotic journey, although there were differences in how they approached the tasks of caregiving. Males struggled more with housekeeping chores and cooking, while women struggled with home and car maintenance tasks. At the same time, they also took pride in their ability to master these new roles. Women, however, were not strong enough physically to provide personal care to husbands who weighed much more than they did. Miller (1996) reported that generally men and women in her study of 215 caregivers acknowledged few gender differences, with the exception of women feeling size worked against them for physical care. She hypothesized that there may be something about the marital relationship that causes spouses to minimize gender differences in caregiving, especially if the couple had long shared household chores (pg. 201).

Just as there was little ethnic or racial diversity to this study, all of the interviews were done with a suburban study population. Although the theory may apply well to urban or geographically diverse populations of spousal caregivers, this study includes only 40 suburban cases, and thus wider application cannot be assumed. However, the related caregiving research shown in the literature review, does suggest universality for most of the caregiver stresses, challenges, and interventions. Cultural differences may dictate subtle changes in the mediating factors of Stage 5-B, but for the most part, the symbiotic stage theory is likely to have some credibility beyond the study population.

What does the symbiotic stage theory add to the literature in terms of support services and interventions? The theory primarily supports two main points related to services: it shows that there are optimal times for the introduction of services to dementia couples; and secondly, that there is a social policy imperative to provide service or instead, to allow the grievous effects of spousal caregiver decline and depression as the relationship becomes toxic.

Optimal Stages for Specific Services

The symbiotic stage theory shows that there are periods in the caregiving and dementia experience where certain needs should be met in order to support both the caregiver and the dementia spouse. The following table identifies these sensitive periods.

Table 6: Stages of Symbiotic Caregiving with Appropriate Services

Stages 3 The Diagnosis	**Stage 4: Commensal Stage**	**Stage 5: Dependent Stage**
Information/Referral from Physician's Office	Support Group for Caregiver	Continuing Counseling Support From Physician's Office
Continuing Counseling Support From Physician's Office	Support Group for Dementia Patient	Adult Day Services for Dementia Spouse
	Driving Assessment for Dementia Patient	Respite Care
	Training for Caregiver Related to ADLs	In Home Health Care for Dementia Spouse
	Continuing Counseling Support From Physician's Office	Long Term Care in a Facility
	Care Management	Support Group for Caregiver
		Care Management

3-1. Stage 3 (Diagnosis and Transition) Support Services and Interventions

Stage 3 of the symbiotic passage is the time for medical intervention, assessment, referral, and diagnosis. At that time, both spouses are usually interacting with the medical professional, when there is a lot of stress for both the couple, and the physician. It is a sensitive period when there is a great need to know, but at the same time, great apprehension, anxiety, and ultimately, anger. Most of this was discussed in Chapter 3.

This stressful period argues for more support directly from the physician or another staff member in the practice. Since the physician is often under pressure to keep the appointment to a certain HMO prescribed time limit, or is ambivalent about how much to share with the couple, and since the diagnosis is at some level, a kind of death sentence, it may be more suitable to have someone positioned within the practice, to step in and meet with the couple following the diagnosis, in order to help them sort out their feelings, options, questions, etc. This health professional could be a Registered Nurse, a Nurse Practitioner, a Social Worker, or some other professional trained in the crisis intervention skills required for this type of interaction. Furthermore, this person could be a source of continuing information and referral as well as counseling support for both the dementia patient, and for the caregiver. Thus, the couple is not sent away with just the basic admonition to “call the Alzheimer’s Association.”

This type of structure is supported by Chappell & Reid’s (2002) study showing perceived social support was positively related to the caregiver’s sense of well being. Kosloski, Young, and Montgomery (1999) found that caregiver’s satisfaction with emotional support was more significant than satisfaction with support for tasks. Studies like this suggest that interventions always need to reassure caregivers and dementia spouses that they do not have to face this diagnosis alone.

The argument for an alternative model of care is not new in the medical literature, and is advocated strongly by Adams et al. (2005): “In order to provide the care our cognitively impaired elders need, it is essential that those who are involved in planning and providing care recognize the need for an expanded model of medical care and reimbursement for these patients” (p. 237-238).

The physician’s office is the most obvious place for the dementia couple to learn more about the diagnosis, voice their fears, receive informational material, and learn about the array of services available to them in their communities. This support may be spaced over several different meetings, since at the time of diagnosis, they may not be able to take in detailed information. With a supportive professional offering to help them navigate the journey ahead, the couple would leave knowing they are not alone. A follow-up appointment would help them discuss their options when they are ready. This professional care manager, based in the primary care physician’s office may continue to follow the couple, or may refer the couple to a private care manager at a later date.

3-2: Stage 4 (Commensalism) Support Services and Interventions

In the commensal stage of caregiving, Stage 4, the couple has adjusted to the new identity, where one spouse is increasingly dependent on the other, and the caregiver spouse is accepting more responsibility for the couple. Aside from the continuing support from the physician's office, the caregiver spouse does need to join a support group. Twenty-five of the interviewees were in support groups, or had been at one time. Of the remaining 15 caregivers, 8 would have used a support group but faced some sort of barrier, such as distance or transportation. The comments as stated in Chapter 5 were overwhelmingly positive about this service, and it was only the more independent individuals who did not choose to go to a support group. The support group, especially if it matches the spousal situation of the caregivers, serves as a kind of umbilical cord for the caregiver. The best groups met during the day, and provided some kind of respite service to the care receivers at the same time, so the caregiver spouses could more freely share their concerns and questions.

The support group that was observed by the investigator included some members who stayed in touch with each other outside of the appointed time. Mostly they spoke by phone, but a few used the internet to communicate, and some even met for coffee or lunch when possible. As is true for other support groups, these members draw more from each other than from the leader. They understand what each other is going through, and are accepting and non-judgmental. The research reflects the benefit of a support group, and has found that groups which allow members opportunities to evaluate the stresses in their caregiving situations, as well as share coping strategies were the most beneficial (Hebert, Levesque, Vezina, Lavoie, Ducharme, Gendron, Preville, Voyer, & Dubois, 2003). One study created such a support group using an internet structure, with good results as well (Marziali & Donahue, 2006

Similarly, there are more "early intervention support groups" forming for early diagnosis dementia patients. Although this study did not address this type of support group, it seems to be a good alternative for the person who is newly diagnosed. The process of assuming a new, and lesser role, in the life of the couple, is unsettling to care receivers, as seen in the anger they express toward the caregivers. Thus, a support group for them in that transitional time would seem to be helpful, for the same reason the support groups for caregivers are helpful.

Of intense concern to caregivers in the commensal stage of caregiving is the automobile driving behavior of the care receiver. As the dementia worsens, so does the driving, ultimately leading to minor accidents, or to the care receiver getting lost, or worse. This point in the dementia caregiving journey is universal, and is a stress point not only for spouses, but for adult children as well. Recent studies related to driving have pointed out some of the issues shown here, adding that older adults generally do not plan for driving cessation (Carr, Shead, & Storandt, 2005). Some communities are piloting assessment services for older drivers. One of the caregivers in the current study participated in an assessment option offered by a local dementia clinic. An internet search turned up in-car driving assessment services in Scotland and in the Boston area, although nothing showed up for New York. Such an assessment by a trained professional would be an excellent service for the family. The dementia spouse would be evaluated for judgment, reaction time, vision, etc. If the one doing the assessment found the dementia spouse to be lagging in the ability to drive, he or she would make the recommendation for the dementia spouse to cease driving, and it would be easier for the dementia spouse to accept. This is probably the most critical issue in this stage of the caregiving passage.

Another service, key to the commensal stage, is training for the caregiver. Most of the researched articles that concerned training emphasized the psycho-social aspects of caregiving, such as maintaining a social network and learning how to deal with problem behaviors (Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003; Drentea, Clahy, Roth, & Mittelman, 2006; Gonyea, O’Connor, & Boyle, 2006; Marziali & Donahue, 2006; Mittelman, Ferris, Shulman, Steinberg, Ambinder, Mackell, & Cohen, 1995; Mittelman, Roth, Haley, & Zarit, 2004; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999). Social networking and coping with problem behaviors are the two areas that provide the most successful intervention strategies. However, there were two interesting training programs that directly addressed training for caregiving. Gitlin, Corcoran, Winter, Boyce, and Hauck (2001) designed an intervention which involved five 90-minute home visits by an occupational therapist, who not only provided training in caregiving, but suggested physical and social environmental modifications to the caregiver. At 3-months post training, the caregivers still were doing better than the control group, and the care receivers as well. The second model program was called “The Savvy Caregiver Program,” and its unique identity was that it was designed to be transportable, specifically in remote areas, without the original designers being present. The original program was 12 hours of training, addressing knowledge, skills, attitudes, as well as self-care (Hepburn, Lewis, Sherman, & Tornatore, 2003). Programs of this type would be well received by the caregivers in this study. Most of the training they received was through their support groups. Several different local Alzheimer’s groups offer annual training conferences for caregivers as well as professionals. They often provide respite care on site for the dementia patients. However, the county, itself, does not have any ongoing training program for dementia caregivers.

3-3: Stage 5 (Toxic or Mediated Dependency) Support Services and Interventions

The last group of support services concerns those caregivers who are in late commensal caregiving, passing into Stage 5, a stage marked by a more intense level of dependency in the relationship. If the services are in place, it is much more likely that the caregiver spouse will be able to continue to care for the dementia spouse, without seeing the relationship grow toxic. Although caregivers may resist, they should be pressed by family or professional care managers, social workers, or physicians to accept services, or face a much more serious alternative. Worst case scenarios are that the caregiver will weaken physically, show signs of depression, self neglect, and perhaps overtly abuse the care receiver. If the caregiver is hoping to be present for their symbiotic partner until death, then he or she must agree to services.

Some of these services have been addressed, such as ongoing counseling or support from a care manager, participation in a support group, and training in how to provide care as the level of care intensity increases. An additional service that should be used, even before this point, if possible, is enrollment of the dementia spouse in adult day services. Usually a dementia spouse would not qualify for a medical day services program, but is a good candidate for a social day services model. Chapter 5 explored, in detail, the experiences of the 40 caregiving couples, 27 of whom had tried adult day care. Of the remaining 13 caregivers, 6 were expecting to try it when their spouses were "ready." For those who used it successfully, the experience was their major form of respite, and many referred to it as a "blessing." Policy that supports caregivers should include this form of respite care. It is more affordable than sending someone into the home, and actually allows the caregiver to clean the house, or just enjoy the house by himself/herself.

Like the support group structure, an adult day services program affords professionals an opportunity to evaluate the status of both caregiver and care receiver. As the potential for toxicity increases, this oversight becomes significant for the well being of both, as well as for informing family members who are not as well trained in detecting changes in psychological status. The health or social work professional can initiate an intervention such as in home health services or respite care which otherwise the caregiver and family may not consider. These services, in turn, provide additional oversight, for they alert the physician, or care manager, if anything is "unhealthy" about the home environment.

In-home services are not just for oversight, but rather to support the ADL needs and health needs of the dementia spouse. As the spouse weakens from the progress of the dementia, he or she often is unable to walk, to get up from a seated position, to "move" as requested, to cooperate with ADLs. This caused a few caregivers in the study to become irritated and impatient, sometimes leading to neglect of the care receiver. Trained spousal caregivers understood the inability of the dementia spouse, but often were not strong enough to provide the assistance required. The in-home aide becomes crucial at this point, especially if other family members are not present, which was the situation for most of the couples. One particularly good example of a supportive service from the caregiving literature was a program of "Evening and Night Patrols for Homebound Elders" in Sweden (Malmberg, Ernsth, Larsson, & Zarit, 2003). Both assistance with ADLs and health care are provided by these patrols, teams made up of a nurse or LPN, along with an aide. Teams cover a certain geographical district, offering aid to dependent persons of any age, although 75% were over 65. Most of the team members were women with an average age of 43.5 (p. 762). Such teams or patrols would be extremely beneficial to spousal caregivers, enabling them to keep their dementia spouses home for a longer period of time. Night care, including dressing and going to bed, are often the tasks that ultimately lead to institutionalization, since the care receiver often falls during the task. With assistance, even the female spouse is more able to perform this task. Without assistance, the female spouse caregiver is sabotaged in her desire to provide care, with a 911 call being the result, and an emergency hospitalization.

Respite care is a service which does currently exist for spousal caregivers, but tends to be in short supply. Informally, spouses often seek respite care from their own families and friends. However, as the years pass, and the needs of the care receiver multiply, caregivers often resist asking for help from family and friends, preferring to use day care as their respite time. For those not attending day care, or without family nearby, respite services are the only way the caregiver has time for himself or herself. Most caregivers in the study wished for more of these services.

Finally, the last service which needs to be in place to support the symbiotic caregiving couple, is long term care in a facility. With other services in place appropriately during the caregiving journey, the time for institutionalization may only be a few days to a year. Sometimes, with hospice support, there may not be any need for long term care at all. However, where the dementia is other than Alzheimer’s disease, the time may be more extended. Still, the symbiosis survives that transition in living arrangements. The couple continues to be bound together, for better or worse. Caregivers find themselves continuing to put in long hours, but this time as visitors, who assisted formal caregivers in the care of their dementia spouses. Though often viewed as a separate stage in the dementia caregiving journey, using the symbiotic stage theory, it is really just one more mediating factor, preventing toxicity in the relationship, and harm to the caregiver. Like the other mediating services, there is an optimal time for accessing the service, once other alternatives are no longer able to support the caregiver to the extent that the progression of the disease demands.

Studies of how caregivers cope with institutionalization generally show that adult child caregivers adjust better than do spousal caregivers, or those who provided care for a longer period of time (Gaugler, Kane, Kane, Clay, & Newcomer, 2005; Schulz, Belle, Czaja, McGinnis, Stevens, & Zhang, 2004; and Tornatore & Grant, 2004). That can be interpreted as one of the effects of the symbiosis. Since it is really only spouses who develop the symbiotic relationship, it is understandable that the physical displacement that occurs through institutionalization would be felt most keenly by spouses. The caregiver in this study who visits her spouse daily, and deals with the inadequate local system of public transportation, in order to spend long hours in a somewhat chaotic and stressful environment, because her husband is there, exemplifies symbiosis.

Policy and Recommendations

Policy implications from this study center on two major areas of concern. The first was the unexpected finding related to medical interactions, showing how significant the medical component is, when looking at stress for dementia caregivers. If caregivers do not get initial support from their medical provider during the period of diagnosis, whatever follows is always patchwork, word-of-mouth, and essentially haphazard. Medical care and dementia services must be linked in some continuum of care design if we are to successfully support the spousal caregiver.

Secondly, caregiving is still viewed as primarily women's work, and women are still the majority of the informal caregivers to older adults. As shown in this study, male caregivers are increasing in number all the time, and this can be expected to continue, especially for spousal caregiving, owing to increases in male longevity. But the fact remains that, not only are women seen as the expected caregivers, their ongoing numbers continue to validate that view. Future policy for caregiving should acknowledge this gender bias, and work to support all caregivers with budget dollars so that not only will caregivers continue to step up to the task, but also to prevent the accusation of exploitation from anyone using a feminist lens. The women, as well as the men, in this study truly wanted to be the caregiver their spouses needed, but their continued effectiveness needs the support of the medical and social service professionals, as well as the funding necessary to enact services such as these listed below.

This study suggests the following recommendations:

1. Information, referral and support should be a service provided by the primary care physician's office, and augmented by the neurologist's office. Initial care management is most appropriate coming from this source, immediately post diagnosis.

2. Support groups are the lifeline for caregivers and should be representative of different models of support, located conveniently, and accessible by public transportation. If possible, there should be respite care provided for the care receiver during the time of the support group. Furthermore, spouses of different age cohorts do not always have enough in common to make the group equally successful. Younger spousal caregivers need a support group more attuned to their needs.

3. Adult Day Services, or Day Care, is a crucial form of respite care for spousal caregivers, therapeutic to the care receivers, and a "blessing" for the caregivers. Linking these programs to the support groups is useful. Supporting the growth and maintenance of these centers through appropriate funding should be a priority of public policy.

4. Care management or collaborative care should emanate from the physician's office, and pass on to a private care manager over time. Care managers help create the support team for the couple, and the extended family. They provide the information not generally available to caregivers or other family members. If the source of this care management uses technology, the service may actually be 24 hours/7 days per week, the perfect framework for the spousal caregiver.

5. Physicians, caregivers, and care receivers need to build a triadic team, overcoming communication barriers, and supporting the dementia journey. Physician training should include practice guidelines for triadic teams. Dementia caregivers should have access to training as well, from caregiver support services, on how to effectively contribute to the triadic team.

There are two additional, secondary recommendations which grew out of this research, related to specific problems that almost all of the caregivers mentioned during the interviews.

6. States should draw up driving cessation guidelines for those with dementia, and provide an assessment service for families to access when they question whether the person with dementia should be driving.

7. Federal, state, and local governments should pass public building codes that mandate personal care, unisex lavatories, so that caregivers can physically accompany their dementia family member for toileting while in public venues.

If these supports are in place for the dementia caregiving couple, American society will not have to apologize for its reliance on spousal caregivers, will not be forced to address feminist criticism for the exploitation of women as caregivers, will not have to build more facilities it cannot staff sufficiently. For indeed, as this study shows, spousal caregivers are becoming the bedrock of dementia caregiving. They never actually choose this role, but rather have it thrust upon them, in the later years of their marital relationship. Perhaps due to the strength and salience of their spousal identity, developed over a span of 25 to 60 years, they immediately join the dementia spouse for the duration. Much like other biological creatures, they allow a process of dependent symbiosis to develop with their dementia spouse, accepting the resulting change in their own social identity, and in their social identity as a couple. Unlike other role changes across the lifespan, generally, this is not anticipated, and certainly not chosen, but rather a deeply organic change, resulting from their spousal identity.

The symbiotic stage theory of the dementia couple’s journey is one that ultimately leads to the complete dependency of the dementia spouse and the resulting accumulation of stress on the well spouse caregiver. The chapters of this study explored and set forth causes of stress, as well as mediators of stress, suggesting that with appropriate mediation, the caregiver can remain in the caregiving dyad without toxicity setting in. The toxicity found in this study was manifested by the failing physical and mental health of the caregiver, suggested in some of the interviews. The dementia journey for the couple is always downward, but not always toxic to the caregiver. Programs, training, and social support that validate the caregiver help to hold off toxicity.

The concluding recommendations for specific supports for caregivers, established in a joint framework between the medical and human services professions, will enable caregivers to do what their spousal relationship drives them to do, in a way that is helpful to their dementia spouse, and not harmful to themselves, caught as they are in the symbiotic relationship.

REFERENCES

Adams, W. L., McIlvain, H. E., Geske, J. A., & Porter, J. L. (2005). Physicians' perspectives on caring for cognitively impaired elders. *The Gerontologist, 45*(2), 231-239.

Alspaugh, M. E. L., Stephens, M. A. P., Townsend, A. L., Zarit, S. H., & Greene, R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress as predictors. *Psychology and Aging, 14*(1), 34-43.

Alzheimer’s Association & National Alliance for Caregiving, (2004). *Families care: Alzheimer's caregiving in the United States 2004*. Retrieved October 9, 2007, 2007, from http://www.caregiving.org/data/alzcaregivers04.pdf.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H. & Whitlach, C. J. (1995). *Profiles in caregiving: the unexpected career.* San Diego, CA: Academic Press.

Anthony-Bergstone, C. R., Zarit, S. H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging, 3*(3), 245-248.

Arai, Y., Zarit, S., Sugiura, M., & Washio, M. (2002). Patterns of outcome of caregiving for the impaired elderly: A longitudinal study in rural Japan. *Aging and Mental Health, 6*(1), 39-46.

Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy, 17*(3), 289-299.

Balsis, S., Carpenter, B. D., & Storandt, M. (2005). Personality change precedes clinical diagnosis of dementia of the Alzheimer's type. *Journal of Gerontology, Psychological Sciences, 60B*(2), 98-101.

Barone, A. D., Yoels, W. C., & Clair, J. M. (1999). How physicians view caregivers: Simmel in the examination room. *Sociological Perspectives, 42*(4), 673-690.

Bedard, M., Molloy, D. W., Squire, L., DuBois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit burden interview: A new short version and screening version. *The Gerontologist, 41*, 652-657.

Blumer, H. (1970). Sociological implications of the thought of George Herbert Mead. In G. P. Stone & H. A. Farberman (Eds.), *Social Psychology Through Symbolic Interaction*. Waltham, MA: Ginn-Blaisdell.

Boise, L., Camicioli, R., Morgan, D. L., Rose, J. H., & Congleton, L. (1999). Diagnosing dementia: Perspectives of primary care physicians. *The Gerontologist, 39*(4), 457-464.

Boucher, D. H. (1985). *The Biology of Mutualism: Ecology and Evolution*. Oxford: Oxford University Press.

Brockman, J. (1995). *The Third Culture: Beyond the Scientific Revolution*. NY: Simon and Schuster.

Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, S. (2003). Transitions in spousal caregiving. *The Gerontologist, 43*(2), 230-241.

Calasanti, T. & Bowen, M. E. (2006). Spousal caregiving and crossing gender boundaries: Maintaining gendered identities. *Journal of Aging Studies/Elsevier, 20*(2006), 253-263.

Canadian Study of Health and Aging Work Group (2002). Patterns and health effects of caring for people with dementia: The impact of changing cognitive and residential status. *The Gerontologist, 42*(5), 643-652.

Carpenter, B. D., & Dave, J. (2004). Disclosing a dementia diagnosis: A review of opinion and practice, and a proposed research agenda. *The Gerontologist, 44*(2), 149-158.

Carr, D. B., Shead, V., & Storandt, M. (2005). Driving cessation in older adults with dementia of the Alzheimer's type. *The Gerontologist, 45*(6), 824-827.

Chappell, N. L., & Reid, R. C. (2002). Burden and well being among caregivers: Examining the distinction. *The Gerontologist, 42*(6), 772-780.

Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B., & Hudson, M. L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *The Gerontologist, 44*(4), 500-507.

Connell, C. M., & Gallant, M. P. (1996). Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness. *Journal of the American Geriatrics Society, 44*(8), 1003-1010.

Cooley, C. H. (1983)[1902]. *Human Nature and the Social Order.* New Brunswick: Transaction Books.

Coon, D.W., Thompson, L., Steffen, A., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia. *The Gerontologist, 43*(5), 678-689.

Davis, B. H. (1984). Women, disability, and feminism: Notes toward a new theory. *Frontiers, 8*(1), 1-5.

Deutsch, M., & Krause, R. M. (1965). *Theories in Social Psychology*. New York: Basic Books.

Drentea, P., Clay, O. J., Roth, D. L., & Mittelman, M. S. (2006). Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. *Social Science and Medicine, 63*(4), 957-967.

Dresser, R., & Whitehouse, P. J. (1994). The incompetent patient on the slippery slope. *The Hastings Center Report, 24*(4), 6-12.

Duck, S., & Lea, M. (1983). Breakdown of personal relationships and the threat to personal identity. In G. M. Breakwell (Ed.), *Threatened Identities*. Chichester: John Wiley & Sons Ltd.

Farberman, H. A., Finch, S. J., Horowitz, B. P., & Lurie, A. (2001). *Informal, unpaid caregiving to New York state elders: A telephone survey*. Stony Brook, NY: Stony Brook University, School of Social Welfare, Center for Aging Policy Research.

Farberman, H. A., Finch, S. J., Huddy, L., Lewis, M., Lurie, A., & Morgan, R. (2003). *A survey of family caregiving to elders in Suffolk County, New York*. Stony Brook, NY: Stony Brook University, School of Social Welfare, Center for Aging Policy Research.

Fontana, A., & Smith, R. W. (1989). Alzheimer's Disease victims: The "unbecoming" of self and the normalization of competence. *Sociological Perspectives, 32*(1), 35-46.

Fortinsky, R. H., Leighton, A., & Wasson, J. H. (1995). Primary care physicians' diagnostic, management, and referral practices for older persons and families affected by dementia. *Research on Aging, 17*(2), 124-148.

Gallagher-Thompson, D., Dal Canto, P. G., Jacob, T., & Thompson, L. W. (2001). A comparison of marital interaction patterns between couples in which the husband does or does not have Alzheimer's Disease. *Journal of Gerontology, Social Sciences, 56B*(3), 140-150.

Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2003). Caregiving and institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist, 43*(2), 219-229.

Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2005). The effects of duration of caregiving on institutionalization. *The Gerontologist, 45*(1), 78-89.

Gaugler, J. E., & Kane, R. L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *Journal of Gerontology, Psychological Sciences, 62B*(1), 38-44.

Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (2003). The onset of dementia caregiving and its longitudinal implications. *Psychology and Aging, 18*(2), 171-180.

George, L. (2000). Well-being and sense of self: What we know and what we need to know. In K. W. H. Schaie (Ed.), *The Evolution of the Aging Self: The Societal Impact on the Aging Process* (First ed., pp. 1-35). New York: Springer Publishing Company, Inc.

Gitlin, L. N., Corcoran, M., Winter, L., Alice, B., & Hauck, W. W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist, 41*(1), 4-14.

Glaser, B.G., & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New York: Aldine De Gruyter.

Glaser, B. G., & Strauss, A. L. (1970). Awareness contexts and social interaction. In G. P. Stone & H. A. Farberman (Eds.), *Social Psychology Through Symbolic Interaction* (pp. 336-348). Waltham, MA: Ginn and Blaisdell.

Glasser, M. & Miller, B. (1998) Caregiver and physician perspectives of medical encounters involving dementia patients. *American Journal of Alzheimer's Disease, March/April, 70-80.*

Goffman, E. (1959). *The Presentation of Self in Everyday Life*. New York: Doubleday.

Goffman, E. (1963). *Stigma: Notes on the Management of a Spoiled Identity*. New York: Simon and Schuster Inc.

Gonyea, J. G., O'Connor, M. K., & Boyle, P. A. (2006). Project CARE: A randomized, controlled trial of a behavioral intervention group for Alzheimer's Disease caregivers. *The Gerontologist, 46*(6827-832).

Goodwin, J. S. (2002). Language and medicine: Thinking and talking about Alzheimer's Disease. *The Gerontologist, 42*(3), 293-296.

Haley, W. E., Clair, J. M., & Saulsberry, K. (1992). Family caregiver satisfaction with medical care of their demented relatives. *The Gerontologist, 32*(2), 219-226.

Haley, W. E., & Pardo, K. M. (1989). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging, 4*(4), 389-392.

Hasselkus, B. R. (1992). The family caregiver as interpreter in the geriatric medical interview. *Medical Anthropology Quarterly, 6*(3), 288-304.

Hatch, L. R. (2005). Gender and ageism. *Generations, 29*(3), 19-24.

Haug, M. R. (1994). Elderly patients, caregivers, and physicians: Theory and research on health care triads. *Journal of Health and Social Behavior, 35*(1), 1-12.

Haug, M. R. (1996). Elements in physician/patient interactions in late life. *Research on Aging, 18*(1), 32-51.

Health Resources and Services Administration, (2004). *Nursing aides, home health aides, and related health care occupations: National and local workforce shortages and associated data needs*. Retrieved October 22, 2007 from ftp://ftp.hrsa.gov/bhpr/nationalcenter/RNandHomeAides.pdf.

Hebert, R., Levesque, L., Vezina, J., Lavoie, J.-P., Ducharme, F., Gendron, C., et al. (2003). Efficacy of a psychoeducative group program for caregivers of demented persons living at home: A randomized controlled trial. *Journal of Gerontology: Social Sciences, 58B*(1), 58-67.

Hepburn, K. W., Lewis, M., Sherman, C. W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist, 43*(6), 908-915.

Holstein, J. A., & Gubrium, J. F. (2000). *The Self We Live By: Narrative Identity in a Postmodern World*. New York: Oxford University Press.

Hooker, K., Bowman, S. R., Coehlo, D. P., Lim, S. R., Kaye, J., Guariglia, R. & Li, F. (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *Journal of Gerontology, Psychological Sciences, 57B*(5), 453-460.

Horner, T. M. (1992). The origin of the symbiotic wish. *Psychoanalytic Psychology, 9*(1), 25-48.

Johnson, N. L. (1998). *The Symbiotic Intelligence Project: Self-organizing knowledge on distributed networks driven by human interaction*. Retrieved October 16, 2007, 2007, from http://ishi.lanl.gov/symintel

Kim, J. J., & Keshian, J. C. (1994). Old old caregivers: A growing challenge for community health nurses. *Journal of Community Health Nursing, 11*(2), 63-70.

Kosloski, K. D., Young, R. F., & Montgomery, R. J. V. (1999). A new direction for intervention with depressed caregivers to Alzheimer's patients. *Family Relations, 48*(4), 373-379.

Kramer, B. J. (1993). Expanding the conceptualization of caregiver coping: The importance of relationship-focused coping strategies. *Family Relations, 4*(4), 383-391.

Kramer, B. J., & Lambert, J. D. (1999). Caregiving as a life course transition among older husbands: A prospective study. *The Gerontologist*, *39*(6), 658-667.

Lewis, A. B., & Landis, B. (1973). *Symbiotic pairings in adults*. Retrieved June 9, 2007, 2007, from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1974-07032-001&site=ehost-live

Lewis, R. D. H. (1998). The impact of the marital relationship on the experience of caring for an elderly spouse with dementia. *Ageing and Society, 18*(2), 209-231.

LoboPrabhu, S., Molinari, V., Arlinghaus, K., Barr, E., & Lomax, J. (2005). Spouses of patients with dementia: How do they stay together "Till Death Do Us Part"? *Journal of Gerontological Social Work, 44*(3/4), 161-174.

Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlatch, C. J. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver. *Journal of Gerontology, Psychological Sciences, 57B*(3), 195-204.

Mahoney, D. F., Cloutterbuck, J., Neary, S., & Zhan, L. (2005). African American, Chinese, and Latino family caregivers' impressions of the onset and diagnosis of dementia: Cross-cultural similarities and differences. *The Gerontologist, 45*(6), 783-792.

Malmberg, B., Ernsth, M., Larsson, B., & Zarit, S. H. (2003). Angels of the night: Evening and night patrols for homebound elders in Sweden. *The Gerontologist, 43*(5), 761-765.

Marziali, E., & Donahue, P. (2006). Caring for others: Internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *The Gerontologist, 46*(3), 398-403.

Mead, G. H. (1962)[1934]. *Mind, Self, and Society: From the Standpoint of a Social Behaviorist*. Chicago: The University of Chicago Press, Ltd.

Meshefedjian, G., McCusker, J., Bellavance, F., & Baumgarten, M. (1998). Factors associated with symptoms of depression among informal caregivers of demented elders in the community. *The Gerontologist, 38*(2), 247-253.

Miller, B. (1996). Beyond gender stereotypes: Spouse caregivers of persons with dementia. *Journal of Aging Studies/Elsevier, 10*(3), 189-204.

Mittelman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J. A., Cohen, J. (1995) A comprehensive support program: effect on depression in spouse-caregivers of AD patients. *The Gerontologist*, *35*(6), 792-802.

Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *Journal of Gerontology: Psychological Sciences, 59B*(1), 27-34.

Montgomery, R. J. V., & Kosloski, K. D. (2000). Family caregiving: change, continuity, and diversity. In M. P. Lawton & R. L. Rubinstein (Eds.), *Interventions in Dementia Care: Toward Improving Quality of Life* (pp. 143-171). New York: Springer Publishing Company, Inc.

Munch, S. (2004). Gender-biased diagnosing of women's medical complaints: Contributions of feminist thought 1970-1995. *Women and Health, 40*(1), 101-121.

Musil, C. M., Morris, D. L., Warner, C. B., & Saeid, H. (2003). Issues in caregivers' stress and providers' support. *Research on Aging, 25*(5), 505-526.

National Alliance for Caregiving & American Association of Retired Persons (2005). *Caregiving in the U.S.* Retrieved October 22, 2007, from http://assets.aarp.org/rgcenter/il/us_caregiving_1.pdf.

O'Brien, J. (2000). Caring for caregivers. *American Family Physician, 62*(12), 2584-2585.

Ory, M. G., Yee, J. L., & Tennstedt, S. L. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In R. Schulz (Ed.), *Handbook of Dementia Caregiving: Evidence-Based Interventions for Family Caregivers*. New York: Springer Publishing Company, Inc.

O'Rourke, N., & Tuokko, H. A. (2003). Psychometric properties of an abridged version of the Zarit Burden Interview within a representative Canadian caregiver sample. *The Gerontologist, 43*(1), 121-127.

Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist, 39*(3), 299-309.

Pearlman, R. A. (1996). Challenges facing physicians and healthcare institutions caring for patients with mental incapacity. *Journal of the American Geriatrics Society, 44*(8), 994-995.

Pillemer, K., & Suitor, J. J. (2000). Social integration and family support: Caregivers to persons with Alzheimer's Disease. In Karl Pillemer, Phyllis Moen, Elaine Wetherington, Nina Glasgow (Ed.), *Social Integration in the Second Half of Life*. Baltimore: Johns Hopkins University Press.

Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45*(1), 90-106.

Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journal of Gerontology, Psychological Sciences, 61B*(1), 33-45.

Powers, D. V., Gallagher-Thompson, D., & Kraemer, H. C. (2002). Coping and depression in Alzheimer's caregivers: Longitudinal evidence of stability. *Journal of Gerontology, Psychological Sciences, 57B*(3), 205-211.

Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *Journal of Gerontology, Psychological Sciences, 59B*(4), 185-190.

Rosack, J. (2006). New diagnostic test may improve dementia care. *Psychiatric News, 41*(23), 24.

Rose-Rego, S. K., Strauss, M. E., & Smyth, K. A. (1998). Differences in the perceived well-being of wives and husbands caring for persons with Alzheimer's Disease. *The Gerontologist, 38*(2), 224-230.

Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. V. (2005). Investigating the effects of communication problems on caregiver burden. *Journal of Gerontology: Social Sciences, 60B*(1), S48-S55.

Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. V. (2006). *Identity maintenance processes of spouse caregivers: Implications for caregiver burden* (Poster at Gerontology Society of America Conference).

Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, *292*(8), 961-967.

Schulz, R., O'Brien A., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35*(6), 771-791.

Seltzer, M. M. L., & Li, L. W. (2000). The Dynamics of caregiving: The transitions during a three-year prospective study. *The Gerontologist, 40*(2), 165-178.

Sharpe, P. A. (1995). Older women and health services: Moving from ageism toward empowerment. *Women and Health*, *22*(3), 9-23.

Skaff, M. M., Pearlin, L. I., & Mullan, J. T. (1996). Transitions in the caregiving career: Effects on sense of mastery. *Psychology and Aging, 11*(2), 247-257.

Stone, G. P., & Farberman, H. A. (1970). *Social Psychology Through Symbolic Interaction*. Waltham, MA: Ginn-Blaisdell.

Stryker, S., & Burke, P. J. (2000). The past, present, and future of identity theory. *Social Psychology Quarterly, 63*(4), 284-297.

Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness, 19*(1), 93-117.

Tennstedt, S. (1999). *Family caregiving in an aging society*. Retrieved October 9, 2007, 2007, from http://www.aoa.gov/prof/research/famcare.pdf.

Tornatore, J., & Grant, L. A. (2004). Family caregiver satisfaction with the nursing home after placement of a relative with dementia. *Journal of Gerontology: Social Sciences, 59B*(2), 80-88.

Wagner, D. L. (1997). *Comparative analysis of caregiver data for caregivers to the elderly 1987 and 1997*. Retrieved October 9, 2007, from http://www.caregiving.org/data/analysis.pdf.

White, T. (1997). Symbiosis and attachment hunger. *Transactional Analysis Journal, 27*(4), 300-304.

Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist, 46*(5), 688-694.

Williams, I. C. (2005). Emotional health of Black and White dementia caregivers: A contextual examination. *Journal of Gerontology, Psychological Sciences, 60B*(6), 287-295.

Williams, O., Keady, J., & Nolan, M. (1995). Younger-onset Alzheimer's Disease: Learning from the experience of one spouse carer. *Journal of Clinical Nursing, 4*, 31-36.

Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist, 40*(2), 147-164.

Zarit, J. (2001). A tribute to adaptability: Mental illness and dementia in intimate late-life relationships. *Generations, 25*(2), 70-74.

Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *Families Under Stress: Caring for the Patient with Alzheimer's Disease and Related Disorders.* New York: University Press.

Zarit, S. H., Reever, K., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*(6), 649-654.

BIBLIOGRAPHY

Actuaries, A. A. O. (1999). *Long-term care: Actuarial issues in designing voluntary federal-private LTC insurance programs*. Retrieved January 7, 2008, from http://www.actuary.org/pdf/health/LTC.pdf

Adams, W. L., McIlvain, H. E., Geske, J. A., & Porter, J. L. (2005). Physicians' perspectives on caring for cognitively impaired elders. *The Gerontologist, 45*(2), 231-239.

Alspaugh, M. E. L., Stephens, M. A. P., Townsend, A. L., Zarit, S. H., & Greene, R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress as predictors. *Psychology and Aging, 14*(1), 34-43.

Alzheimer’s Association & National Alliance for Caregiving, (2004). *Families care: Alzheimer's caregiving in the United States 2004*. Retrieved October 9, 2007, from http://www.caregiving.org/data/alzcaregivers04.pdf

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H. & Whitlach, C. J. (1995). *Profiles in caregiving: the unexpected career.* San Diego, CA: Academic Press.

Anthony-Bergstone, C. R., Zarit, S. H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging, 3*(3), 245-248.

Arai, Y., Zarit, S., Sugiura, M., & Washio, M. (2002). Patterns of outcome of caregiving for the impaired elderly: A longitudinal study in rural Japan. *Aging and Mental Health, 6*(1), 39-46.

Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy, 17*(3), 289-299.

Balsis, S., Carpenter, B. D., & Storandt, M. (2005). Personality change precedes clinical diagnosis of dementia of the Alzheimer's type. *Journal of Gerontology, Psychological Sciences, 60B*(2), 98-101.

Barone, A. D., Yoels, W. C., & Clair, J. M. (1999). How physicians view caregivers: Simmel in the examination room. *Sociological Perspectives, 42*(4), 673-690.

Bedard, M., Molloy, D. W., Squire, L., DuBois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit burden interview: A new short version and screening version. *The Gerontologist, 41*, 652-657.

Blumer, H. (1970). Sociological implications of the thought of George Herbert Mead. In G. P. Stone & H. A. Farberman (Eds.), *Social Psychology Through Symbolic Interaction*. Waltham, MA: Ginn-Blaisdell.

Boise, L., Camicioli, R., Morgan, D. L., Rose, J. H., & Congleton, L. (1999). Diagnosing dementia: Perspectives of primary care physicians. *The Gerontologist, 39*(4), 457-464.

Boucher, D. H. (1985). *The Biology of Mutualism: Ecology and Evolution*. Oxford: Oxford University Press.

Brockman, J. (1995). *The Third Culture: Beyond the Scientific Revolution*. NY: Simon and Schuster.

Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *The Gerontologist, 46*(1), 52-61.

Burke, C. (2007, August 17, 2007). *Medicaid and state budgets: Clearing storm, foggy forecast*. Retrieved January 7, 2008, 2008, from http://www.rockinst.org/WorkArea/showcontent.aspx?id=12122

Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, S. (2003). Transitions in spousal caregiving. *The Gerontologist, 43*(2), 230-241.

Calasanti, T. & Bowen, M. E. (2006). Spousal caregiving and crossing gender boundaries: Maintaining gendered identities. *Journal of Aging Studies/Elsevier, 20*(2006), 253-263.

Calasanti, T., & King, N. (2007). Taking 'women's work' 'like a man': Husbands' experiences of care work. *The Gerontologist, 47*(4), 516-527.

Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, A. J., et al. (2006). Effectiveness of collaborative care for older adults with Alzheimer’s Disease in primary care: A randomized controlled trial. *Journal of the American Medical Association, 295*(18), 2148-2157.

Canadian Study of Health and Aging Work Group, (2002). Patterns and health effects of caring for people with dementia: The impact of changing cognitive and residential status. *The Gerontologist, 42*(5), 643-652.

Carpenter, B. D., & Dave, J. (2004). Disclosing a dementia diagnosis: A review of opinion and practice, and a proposed research agenda. *The Gerontologist, 44*(2), 149-158.

Carr, D. B., Shead, V., & Storandt, M. (2005). Driving cessation in older adults with dementia of the Alzheimer's type. *The Gerontologist*, *45*(6), 824-827.

Chappell, N. L., & Reid, R. C. (2002). Burden and well being among caregivers: Examining the distinction. *The Gerontologist, 42*(6), 772-780.

Christakis, N. A., & Allison, P. D. (2006). Mortality after the hospitalization of a spouse. *New England Journal of Medicine, 354*(7), 719-730.

Cohen, M. A., Miller, J., & Weinrobe, M. (2001). Patterns of informal and formal caregiving among elders with private long-term care insurance. *The Gerontologist, 41*(2), 180-187.

Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B., & Hudson, M. L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *The Gerontologist*, *44*(4), 500-507.

Connell, C. M., & Gallant, M. P. (1996). Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness. *Journal of the American Geriatrics Society, 44*(8), 1003-1010.

Cooley, C. H. (1983) [1902]. *Human Nature and the Social Order*. New Brunswick: Transaction Books.

Coon, D.W., Thompson, L., Steffen, A., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia. *The Gerontologist*, *43*(5), 678-689.

Davey, A., Femia, E., Zarit, S. H., Shea, D. g., Sundstrom, G., Berg, S., et al. (2005). Life on the edge: Patterns of formal and informal help to older adults in the United States and Sweden. *Journal of Gerontology: Social Sciences, 60B*(5), 281-288.

Davis, B. H. (1984). Women, disability, and feminism: Notes toward a new theory. *Frontiers, 8*(1), 1-5.

Deutsch, M., & Krause, R. M. (1965). *Theories in Social Psychology*. New York: Basic Books.

Drentea, P., Clay, O. J., Roth, D. L., & Mittelman, M. S. (2006). Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. *Social Science and Medicine, 63*(4), 957-967.

Dresser, R., & Whitehouse, P. J. (1994). The incompetent patient on the slippery slope. *The Hastings Center Report*, *24*(4), 6-12.

Duck, S., & Lea, M. (1983). Breakdown of personal relationships and the threat to personal identity. In G. M. Breakwell (Ed.), *Threatened Identities*. Chichester: John Wiley & Sons Ltd.

Eaton, S. (2003). Frontline caregivers in nursing facilities: Can policy help in recruitment and retention crisis? *Public Policy and Aging Report, 13*(2), 8-11.

Farberman, H. A., Finch, S. J., Horowitz, B. P., & Lurie, A. (2001). *Informal, unpaid caregiving to New York state elders: A telephone survey*. Stony Brook, NY: Stony Brook University, School of Social Welfare, Center for Aging Policy Research.

Farberman, H. A., Finch, S. J., Huddy, L., Lewis, M., Lurie, A., & Morgan, R. (2003). *A survey of family caregiving to elders in Suffolk County, New York*. Stony Brook, NY: Stony Brook University, School of Social Welfare, Center for Aging Policy Research.

Family Caregiver Alliance, (2006). *Caregiver health*. Retrieved October 23, 2007, from http://www.caregiver.org/caregiver/jsp/home.jsp.

Fisher, L., & Lieberman, M. A. (1999). A longitudinal study of predictors of nursing home placement for patients with dementia: The contribution of family characteristics. *The Gerontologist, 39*(6), 677-686.

Fontana, A., & Smith, R. W. (1989). Alzheimer's Disease victims: The "unbecoming" of self and the normalization of competence. *Sociological Perspectives, 32*(1), 35-46.

Fortinsky, R. H., Leighton, A., & Wasson, J. H. (1995). Primary care physicians' diagnostic, management , and referral practices for older persons and families affected by dementia. *Research on Aging, 17*(2), 124-148.

Gallagher-Thompson, D., Dal Canto, P. G., Jacob, T., & Thompson, L. W. (2001). A comparison of marital interaction patterns between couples in which the husband does or does not have Alzheimer's Disease. *Journal of Gerontology, Social Sciences, 56B*(3), 140-150.

Gaugler, J. E., & Kane, R. L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *Journal of Gerontology, Psychological Sciences, 62B*(1), P38-P44.

Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2003). Caregiving and institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist, 43*(2), 219-229.

Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2005). The effects of duration of caregiving on institutionalization. *The Gerontologist*, *45*(1), 78-89.

Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (2003). The onset of dementia caregiving and its longitudinal implications. *Psychology and Aging, 18*(2), 171-180.

George, L. (2000). Well-being and sense of self: What we know and what we need to know. In K. W. H. Schaie (Ed.), *The Evolution of the Aging Self: The Societal Impact on the Aging Process* (First ed., pp. 1-35). New York: Springer Publishing Company, Inc.

Giesen, C. B., & Datan, N. (1980). The competent older woman. In N. Datan & N. Lohmann (Eds.), *Transitions of Aging* (pp. 57-72). New York: Academic Press.

Gill, C., Hinrichsen, G. A., & DiGiuseppe, R. (1991). Factors associated with formal service use by family members of patients with dementia. *Journal of Applied Gerontology, 17*(1), 38-53.

Gitlin, L. N., Corcoran, M., Winter, L., Alice, B., & Hauck, W. W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist, 41*(1), 4-14.

Gitlin, L. N., Reever, K., Dennis, M. P., Mathieu, E., & Hauck, W. W. (2006). Enhancing quality of life of families who use adult day services: Short-and long-term effects of the Adult Day Services Plus Program. *The Gerontologist, 46*(5), 630-639.

Glaser, B.G., & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New York: Aldine De Gruyter.

Glaser, B. G., & Strauss, A. L. (1970). Awareness contexts and social interaction. In G. P. Stone & H. A. Farberman (Eds.), *Social Psychology Through Symbolic Interaction* (pp. 336-348). Waltham, MA: Ginn and Blaisdell.

Glasser, M. & Miller, B. (1998) Caregiver and physician perspectives of medical encounters involving dementia patients. *American Journal of Alzheimer's Disease*, March/April, 70-80.

Goffman, E. (1959). *The Presentation of Self in Everyday Life*. New York: Doubleday.

Goffman, E. (1963). *Stigma: Notes on the Management of a Spoiled Identity*. New York: Simon and Schuster Inc.

Gonyea, J. G., O'Connor, M. K., & Boyle, P. A. (2006). Project CARE: A randomized, controlled trial of a behavioral intervention group for Alzheimer's Disease caregivers. *The Gerontologist, 46*(6827-832).

Goodwin, J. S. (2002). Language and medicine: Thinking and talking about Alzheimer's Disease. *The Gerontologist, 42*(3), 293-296.

Haley, W. E., Clair, J. M., & Saulsberry, K. (1992). Family caregiver satisfaction with medical care of their demented relatives. *The Gerontologist, 32*(2), 219-226.

Haley, W. E., & Pardo, K. M. (1989). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging, 4*(4), 389-392.

Hasselkus, B. R. (1992). The family caregiver as interpreter in the geriatric medical interview. *Medical Anthropology Quarterly, 6*(3), 288-304.

Hatch, L. R. (2005). Gender and ageism. *Generations, 29*(3), 19-24.

Haug, M. R. (1994). Elderly patients, caregivers, and physicians: Theory and research on health care triads. *Journal of Health and Social Behavior, 35*(1), 1-12.

Haug, M. R. (1996). Elements in physician/patient interactions in late life. *Research on Aging, 18*(1), 32-51.

Health Resources and Services Administration, (2004). *Nursing aides, home health aides, and related health care occupations: National and local workforce shortages and associated data needs*. Retrieved October 22, 2007 from ftp://ftp.hrsa.gov/bhpr/nationalcenter/RNandHomeAides.pdf.

Hebert, R., Levesque, L., Vezina, J., Lavoie, J.-P., Ducharme, F., Gendron, C., et al. (2003). Efficacy of a psychoeducative group program for caregivers of demented persons living at home: A randomized controlled trial. *Journal of Gerontology: Social Sciences, 58B*(1), 58-67.

Hepburn, K. W., Lewis, M., Sherman, C. W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist, 43*(6), 908-915.

Hesse, E. (2005). PRO DEM: A community-based approach to care for dementia. *Health Care Financing Review, 27*(1), 89-94.

Holstein, J. A., & Gubrium, J. F. (2000). *The Self We Live By: Narrative Identity in a Postmodern World*. New York: Oxford University Press.

Hooker, K., Bowman, S. R., Coehlo, D. P., Lim, S. R., Kaye, J., Guariglia, R. & Li, F. (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *Journal of Gerontology, Psychological Sciences, 57B*(5), 453-460.

Horner, T. M. (1992). The origin of the symbiotic wish. *Psychoanalytic Psychology, 9*(1), 25-48.

Hoyert, d. L., & Seltzer, M. M. L. (1992). Factors related to the well-being and life activities of family caregivers. *Family Relations, 41*(1), 74-81.

Johnson, N. L. (1998). *The Symbiotic Intelligence Project: Self-organizing knowledge on distributed networks driven by human interaction*. Retrieved October 16, 2007, 2007, from http://ishi.lanl.gov/symintel

Kim, J. J., & Keshian, J. C. (1994). Old old caregivers: A growing challenge for community health nurses. *Journal of Community Health Nursing, 11*(2), 63-70.

Kosloski, K. D., & Montgomery, R. J. V. (1995). The impact of respite use on nursing home placement. *The Gerontologist, 35*(1), 67-74.

Kosloski, K. D., Young, R. F., & Montgomery, R. J. V. (1999). A new direction for intervention with depressed caregivers to Alzheimer's patients. *Family Relations, 48*(4), 373-379.

Kramer, B. J. (1993). Expanding the conceptualization of caregiver coping: The importance of relationship-focused coping strategies. *Family Relations, 4*(4), 383-391.

Kramer, B. J., & Lambert, J. D. (1999). Caregiving as a life course transition among older husbands: A prospective study. *The Gerontologist, 39*(6), 658-667.

Kunzman, U., Little, T., & Smith, J. (2002). Perceiving control: A double-edged sword in old age. *Journal of Gerontology, Psychological Sciences, 57B*(6), 484-491.

Lewin Group, The, (2001) *Meeting caregiver needs: The right service at the right time.* Report from Administration on Aging, Department of Health and Human Services.

Lewis, A. B., & Landis, B. (1973). *Symbiotic pairings in adults*. Retrieved June 9, 2007, 2007, from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1974-07032-001&site=ehost-live.

Lewis, R. D. H. (1998). The impact of the marital relationship on the experience of caring for an elderly spouse with dementia. *Ageing and Society*, *18*(2), 209-231.

LoboPrabhu, S., Molinari, V., Arlinghaus, K., Barr, E., & Lomax, J. (2005). Spouses of patients with dementia: How do they stay together "Till Death Do Us Part"? *Journal of Gerontological Social Work, 44*(3/4), 161-174.

Lynch, S. A. (1998). Who supports whom? How age and gender affect the perceived quality of support from family and friends. *The Gerontologist*, *38*(2), 231-238.

Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlatch, C. J. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver. *Journal of Gerontology, Psychological Sciences, 57B*(3), 195-204.

Mahoney, D. F., Cloutterbuck, J., Neary, S., & Zhan, L. (2005). African American, Chinese, and Latino family caregivers' impressions of the onset and diagnosis of dementia: Cross-cultural similarities and differences. *The Gerontologist, 45*(6), 783-792.

Malmberg, B., Ernsth, M., Larsson, B., & Zarit, S. H. (2003). Angels of the night: Evening and night patrols for homebound elders in Sweden. *The Gerontologist, 43*(5), 761-765.

Marziali, E., & Donahue, P. (2006). Caring for others: Internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *The Gerontologist, 46*(3), 398-403.

Masters, J. (2006). The benefits of consumer-directed services for caregivers of persons with Alzheimer's Disease. *Families in Society: The Journal of Contemporary Social Services*, *87*(4), 583-589.

McCann, J. J., Hebert, L. E., Li, Y., Wolinsky, F. D., Gilley, D. W., Aggarwal, N. T., & Evans, D. (2005). The effect of adult day care services on time to nursing home placement in older adults with Alzheimer's Disease. *The Gerontologist, 45*(6), 754-763.

Mead, G. H. (1962)[1934]. *Mind, Self, and Society: From the Standpoint of a Social Behaviorist*. Chicago: The University of Chicago Press, Ltd.

Meshefedjian, G., McCusker, J., Bellavance, F., & Baumgarten, M. (1998). Factors associated with symptoms of depression among informal caregivers of demented elders in the community. *The Gerontologist, 38*(2), 247-253.

Miller, B. (1990). Gender differences in spouse caregiver strain: Socialization and role explanations. *Journal of Marriage and the Family*, *52*, 311-321.

Miller, B. (1996). Beyond gender stereotypes: Spouse caregivers of persons with dementia. *Journal of Aging Studies/Elsevier, 10*(3), 189-204.

Miller, B., Townsend, A. L., Carpenter, E., Montgomery, R. J. V., Stull, D., & Young, R. F. (2001). Social support and caregiver distress: A replication analysis. *Journal of Gerontology: Social Sciences, 56B*(4), 249-256.

Mittelman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J. A., Cohen, J. (1995) A comprehensive support program: effect on depression in spouse-caregivers of AD patients. *The Gerontologist, 35*(6), 792-802.

Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *Journal of Gerontology: Psychological Sciences, 59B*(1), 27-34.

Montgomery, R. J. V., & Datwyler, M. M. (1990). Women and men in the caregiving role. *Generations, 14*(3), 34-38.

Montgomery, R. J. V., & Kosloski, K. D. (2000). Family caregiving: change, continuity, and diversity. In M. P. Lawton & R. L. Rubinstein (Eds.), *Interventions in Dementia Care: Toward Improving Quality of Life* (pp. 143-171). New York: Springer Publishing Company, Inc.

Mullan, J. T. (1993). Barriers to the use of formal services among Alzheimer's caregivers. In L. I. Pearlin, K. W. H. Schaie & S. H. Zarit (Eds.), *Caregiving Systems: Informal and Formal Helpers* (pp. 241-261). Hillsdale, NJ: Lawrence Erlbaum Associates.

Munch, S. (2004). Gender-biased diagnosing of women's medical complaints: Contributions of feminist thought 1970-1995. *Women and Health, 40*(1), 101-121.

Musil, C. M., Morris, D. L., Warner, C. B., & Saeid, H. (2003). Issues in caregivers' stress and providers' support. *Research on Aging, 25*(5), 505-526.

National Alliance for Caregiving & American Association of Retired Persons (2005). *Caregiving in the U.S.* Retrieved October 22, 2007, from http://assets.aarp.org/rgcenter/il/us_caregiving_1.pdf.

O'Brien, J. (2000). Caring for caregivers. *American Family Physician, 62*(12), 2584-2585.

O'Rourke, N., & Tuokko, H. A. (2003). Psychometric properties of an abridged version of the Zarit Burden Interview within a representative Canadian caregiver sample. *The Gerontologist, 43*(1), 121-127.

Ory, M. G., Yee, J. L., & Tennstedt, S. L. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In R. Schulz (Ed.), *Handbook of Dementia Caregiving: Evidence-Based Interventions for Family Caregivers*. New York: Springer Publishing Company, Inc.

Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist, 39*(3), 299-309.

Pearlman, R. A. (1996). Challenges facing physicians and healthcare institutions caring for patients with mental incapacity. *Journal of the American Geriatrics Society, 44*(8), 994-995.

Pillemer, K., & Suitor, J. J. (2000). Social integration and family support: Caregivers to persons with Alzheimer's Disease. In K. Pillemer, P. Moen, E.Wetherington, N. Glasgow (Ed.), *Social Integration in the Second Half of Life*. Baltimore: Johns Hopkins University Press.

Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45*(1), 90-106.

Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journal of Gerontology, Psychological Sciences, 61B*(1), 33-45.

Pinquart, M., & Sorensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology, Psychological Sciences, 62B*(2), 126-137.

Powers, D. V., Gallagher-Thompson, D., & Kraemer, H. C. (2002). Coping and depression in Alzheimer's caregivers: Longitudinal evidence of stability. *Journal of Gerontology, Psychological Sciences, 57B*(3), 205-211.

Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *Journal of Gerontology, Psychological Sciences, 59B*(4), 185-190.

Rosack, J. (2006). New diagnostic test may improve dementia care. *Psychiatric News, 41*(23), 24.

Rose-Rego, S. K., Strauss, M. E., & Smyth, K. A. (1998). Differences in the perceived well-being of wives and husbands caring for persons with Alzheimer's Disease. *The Gerontologist, 38*(2), 224-230.

Russell, R. (2001). In sickness and in health: A qualitative study of elderly men who care for wives with dementia. *Journal of Aging Studies/Elsevier, 15*(4), 351-367.

Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. V. (2005). Investigating the effects of communication problems on caregiver burden. *Journal of Gerontology: Social Sciences, 60B*(1), S48-S55.

Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. V. (2006). *Identity maintenance processes of spouse caregivers: Implications for caregiver burden* (Poster at Gerontology Society of America Conference).

Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, *292*(8), 961-967.

Schulz, R., O'Brien A., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35*(6), 771-791.

Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., Belle, S. H., Burgio, L, Gitlin, L, Coon, D., Burns, R., Gallagher-Thompson, D., & Stevens, A. (2002). Dementia caregiver intervention research: in search of clinical significance. *The Gerontologist*, *42*(5), 589-602.

Seltzer, M. M. L., & Li, L. W. (2000). The Dynamics of caregiving: The transitions during a three-year prospective study. *The Gerontologist, 40*(2), 165-178.

Sharpe, P. A. (1995). Older women and health services: Moving from ageism toward empowerment. *Women and Health, 22*(3), 9-23.

Skaff, M. M., Pearlin, L. I., & Mullan, J. T. (1996). Transitions in the caregiving career: Effects on sense of mastery. *Psychology and Aging*, *11*(2), 247-257.

Smith, T. L., & Toseland, R. W. (2006). The effectiveness of a telephone support program for caregivers of frail older adults. *The Gerontologist*, *46*(5), 620-629.

Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, *42*(3), 356-372.

Steffen, A. M., McKibbin, C., Zeiss, A. M., Gallagher-Thompson, D., Bandura, A. (2002). The revised scale for caregiving self-efficacy: reliability and validity studies. *Journals of Gerontology, Psychological Sciences, 57B* (1), 74-86.

Stephens, M. A. P., & Zarit, S. H. (1989). Symposium: Family caregiving to dependent older adults: Stress, appraisal, and coping. *Psychology and Aging, 4*(4), 387-388.

Stone, G. P., & Farberman, H. A. (1970). *Social Psychology Through Symbolic Interaction*. Waltham, MA: Ginn-Blaisdell.

Stryker, S., & Burke, P. J. (2000). The past, present, and future of identity theory. *Social Psychology Quarterly, 63*(4), 284-297.

Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness, 19*(1), 93-117.

Tennstedt, S. (1999). *Family caregiving in an aging society*. Retrieved October 9, 2007, 2007, from http://www.aoa.gov/prof/research/famcare.pdf

Tornatore, J., & Grant, L. A. (2004). Family caregiver satisfaction with the nursing home after placement of a relative with dementia. *Journal of Gerontology: Social Sciences, 59B*(2), 80-88.

Upton, N., & Reed, V. (2005). Caregiver coping in dementing illness--implications for short-term respite care. *The International Journal of Psychiatric Nursing Research, 10*(3), 1182-1196.

Wagner, D. L. (1997). *Comparative analysis of caregiver data for caregivers to the elderly 1987 and 1997*. Retrieved October 9, 2007, from http://www.caregiving.org/data/analysis.pdf.

Walker, D. M. (2002). *Long term care: Aging baby boom generation will increase demand and burden on federal and state budgets.* (Testimony before Special Committee on Aging, U. S. Senate). Washington D.C.: Government Accounting Office.

Weuve, J. L., Boult, C., & Morishita, L. (2000). The effects of outpatient geriatric evaluation and management on caregiver burden. *The Gerontologist, 40*(4), 429-436.

White, T. (1997). Symbiosis and attachment hunger. *Transactional Analysis Journal, 27*(4), 300-304.

Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist, 46*(5), 688-694.

Williams, I. C. (2005). Emotional health of Black and White dementia caregivers: A contextual examination. *Journal of Gerontology, Psychological Sciences, 60B*(6), 287-295.

Williams, O., Keady, J., & Nolan, M. (1995). Younger-onset Alzheimer's Disease: Learning from the experience of one spouse carer. *Journal of Clinical Nursing, 4*, 31-36.

Wolff, J. L., & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist, 46*(3), 344-356.

Wolinsky, F. D., Wyrwich, K. W., Babu, A. N., Kroenke, K., & Tierney, W. M. (2003). Age, aging, and the sense of control among older adults: A longitudinal reconsideration. *Journal of Gerontology, Social Sciences*, *58B*(4), 212-220.

Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and Analysis. *The Gerontologist, 40*(2), 147-164.

Zank, S., & Schacke, C. (2002). Evaluation of geriatric day care units: Effects on patients and caregivers. *Journal of Gerontology, Psychological Sciences*, *57B*(4), 348-357.

Zarit, J. (2001). A tribute to adaptability: Mental illness and dementia in intimate late-life relationships. *Generations, 25*(2), 70-74.

Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *Families Under Stress: Caring for the Patient with Alzheimer's Disease and Related Disorders.* New York: University Press.

Zarit, S. H., Reever, K., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*(6), 649-654.

Zarit, S. H., Stephens, M. A. P., Townsend, A. L., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology: Social Sciences*, *53B*(5), 267-277.

Zarit, S. H., Stephens, M. A. P., Townsend, A. L., Greene, R., Femia, E., Zank, S., (2003). Commentary on "Evaluation of geriatric day care units: Effects on patients and caregivers" and Authors' Reply. *Journal of Gerontology: Psychological Sciences, 58B*(3), 195-199.

Appendix I: Consent Form

Project Title: Spousal Caregiver Study

Principal Investigator: Harvey A. Farberman, Ph.D.
Study Coordinator: Carolyn Gallogly, M.A., Doctoral Candidate
Center for Aging Policy Research, School of Social Welfare, Stony Brook University

Research Consent Form

You are being asked to be a volunteer in a research study.

Purpose: The purpose of this study is to explore issues of caregiver identity and need by interviewing 40 or more older adult spousal caregivers who report that they perceive their care receiver to have some degree of cognitive impairment.

1. *How was I chosen?* You were chosen because you are providing care for your spouse.
2. *What will be involved in participating?* If you decide to be in this study, your part will involve a 1 ½ hour interview at a time of your choosing. The interview will be audio-recorded. These recordings will be transcribed, with all personal identifiers removed. At the conclusion of the study all recordings will be destroyed.

3. *What risks or discomforts are associated with participation in this study?* Generally, there are no risks associated with participation in this study, but the following risks or discomforts may occur as a result of your participation in this study. Some questions asked during the interview may be upsetting and cause increased stress. The discomfort should be temporary in nature. If such is the case for you, you can pause or terminate the interview at any time. Please be assured that the interviewer will respect your needs with sensitivity.

4. *What benefits are associated with participation in this study?* There may be no foreseeable benefit to you as a result of being in this study. A possible benefit to you is that you will receive information about supports for caregivers on Long Island.
5. *Is there any payment for participation in this study?* Payment: There is no payment to you for participation in this study. This is an unfunded research study.

6. *Will the interview be confidential*? Confidentiality: The following procedures will be followed in an effort to keep your personal information confidential in this study. Your identity will be coded by a number, not by your name. The linking information is kept separate in a locked file and identifiers will be destroyed when the study is complete. All data will be kept in a secured, limited access location. Your identity will not be revealed in any publication or presentation of the results of this research. Confidentiality cannot be

guaranteed; your personal information may be disclosed if required by law. This means that there may be rare situations that require us to release personal information about you, for example, in case a judge requires such release in a lawsuit or if you tell us of your intent to harm yourself or others (including reporting behaviors consistent with child abuse.) To ensure that this research activity is being conducted properly, Stony Brook University's Committee on Research Involving Human Subjects, Stony Brook legal counsel, OHRP (Office for Human Research Protections in Washington, DC), have the right to review study records, but confidentiality will be maintained as allowed by law.

7. *Is there any cost to me?* There is no foreseeable cost to you, other than the time it takes for you to participate in the interview.

8. *Is there any alternative to participating in this study?* The alternative is not to participate in the study.

9. *What are my rights as a respondent?*

- Your participation in this study is voluntary. You do not have to be in this study if you don't want to be.
- You have the right to change your mind and leave the study at any time without giving any reason, and without penalty.
- Any new information that may make you change your mind about being in this study will be given to you.
- You will get a copy of this consent form to keep.
- You do not waive any of your legal rights by signing this consent form.

6. *If I have questions about the study or my rights as a research subject, whom can I contact about the study?* This study has been approved by the Committee on Research Involving Human Subjects at Stony Brook University.

- If you have any questions about the study, you may contact Dr. Harvey A. Farberman, (631) 444-8361.
- If you have any questions about your rights as a research subject, you may contact Ms. Judy Matuk, Committee on Research Involving Human Subjects, (631) 632-9036.

If you sign below, it means that you have read (or have had read to you) the information given in this consent form, and you would like to be a volunteer in this study.

Subject Name (Please Print.) ________________________________

Subject Signature ________________________________ Date ___________________

Signature of Person Obtaining Consent _______________ Date ___________________
Printed Name of Person Obtaining Consent Carolyn Gallogly
Please place your initials here acknowledging receipt of a copy of this consent form. ___

Appendix II: Interview Guide

Background Questions

1. Can you tell me your story as a spousal caregiver?

2. What were the first signs that your spouse was experiencing a cognitive impairment?

How did you both react?

How did your family react?
(This section can be quite lengthy, and the interviewee will be able to go wherever she/he likes.)

Identity Questions

3. When did you first know that you were a caregiver?

Can you recall anything about that specific moment or event when you knew you were a caregiver?

Can you describe feelings you might have had at that point?

4. When do you think your care receiver first knew that you were his/her caregiver?

What did he or she say or do to make you think this was the moment or event?

5. What is a typical day for the two of you?

What experiences can you still share?
What experiences do you miss the most?

6. Of all the changes that caregiving has made in your daily experiences, what changes are the most challenging, or hardest?

What are the most rewarding changes in your daily experience because you have become a caregiver?

7. How has your relationship with the care receiver changed since you became his/her caregiver?
Do you look at him/her in a different way?

Do you see yourself differently?
Or do you think you have changed, and if so, in what way?
8. Do you think the care receiver looks at you differently? (Or do you think he/she looks at you in a different way?)

9. You are a married couple. Do you think others in your family see you two differently as a couple, now that your spouse needs care?

How do they fit into this picture?

10. How do you react to your spouse's difficult behaviors?

How do you cope?

11. Is there any activity that you continue to do by yourself? How do you manage this, given your caregiving responsibilities?

Service and Support Questions

11. Is there anything that you currently do for your spouse that you really wish someone else would do?

12. Who do you turn to for help?

13. Do you use any of the services available to caregivers?

How did you learn about this service?

What made you decide to ask for this service?

14. Is there any available service that you purposely do not use?

Why?

15. If you could design one service, which you currently do not have, what would it be?

16. Is there any service that the county should provide to make it easier for you to cope with caregiving?

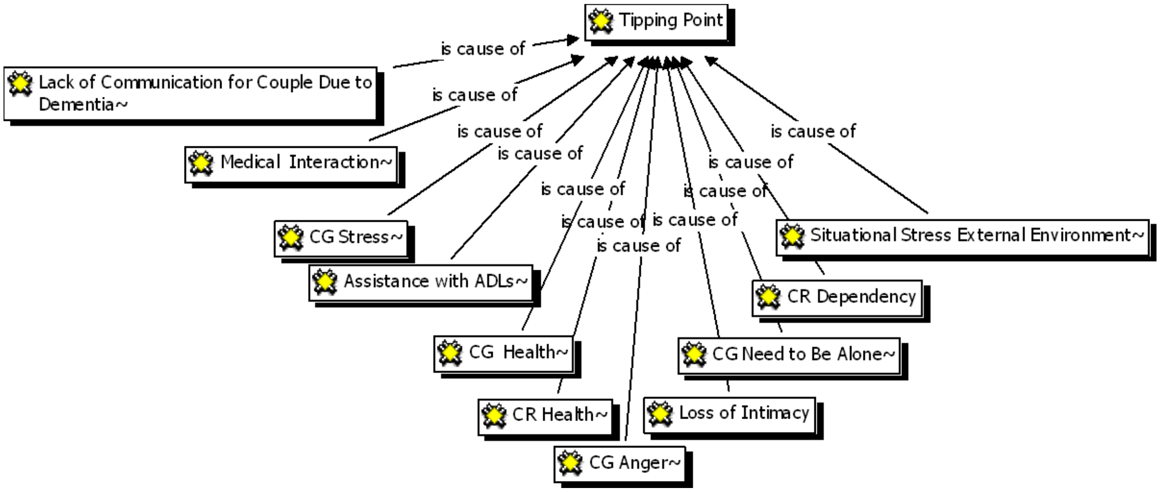
17. Have you given any thought to the future?

Appendix III: List of Codes

Adult Children
Adult Day Care
Assistance with ADLs
Biggest challenge to CG (CareGiver)
CG Health
CG Humor
CG Lack of Mastery
CG Mastery
CG Anger
CG Assertiveness
CG Create-a-Service
CG Driven Supports
CG Identity
CG Identity/Self Perceived
CG Need to Be Alone
CG Personal Activities
CG Stress
Computer as Source of Support and Info
Couple History
CR & Driving Issue (Care Receiver)
CR Activities
CR Anger and Agitation
CR Dependency
CR Doesn't Know CG
CR Former Identity
CR Health
CR Identity
CR Lack of Mastery
CR Mastery
CR Physical Response
CR Repetitive Behaviors
CR Stress and/or fear
Disrespect from physician/ social worker/ nurse
Early Disregard by Physician
Extended Family
Faith
First signs of Alzheimer’s
Friends and Neighbors Support
Grandchildren
Helpful Strangers/Guardian Angels
Home Chores Pressure
In-Home Services
Incident/time when CG knew he/she was the CG
Incident/time when CR Knew spouse was CG
Incomplete information from physician
Intimacy
Lack of Communication for Couple Because of Dementia
Lack of Cooperation from physician/office staff
Lack of support from physician/others
Loss of Intimacy
Medical Interaction
Medication issues
Negative MI (Medical Interaction)
Neurologist Lack of Rapport
Neutral MI
Not meeting CG expectations for Treatment
Office Personnel
Personal Coping Activities
Poor Facilities
Poor Medical Care
Poor Nursing Care
Poor Personal Care
Positive MI
Positive Outcome
Prior Caregiving Experience
Problem Solving
Protect Dignity of Spouse
Public episode
Quick to diagnose
Role Reversal Incident
Situational Stress External Environment
Support Group
Supportive Children
Supportive Services
Thinking about Future
Tipping Point
Underestimating Dementia Effects
Worry about finances

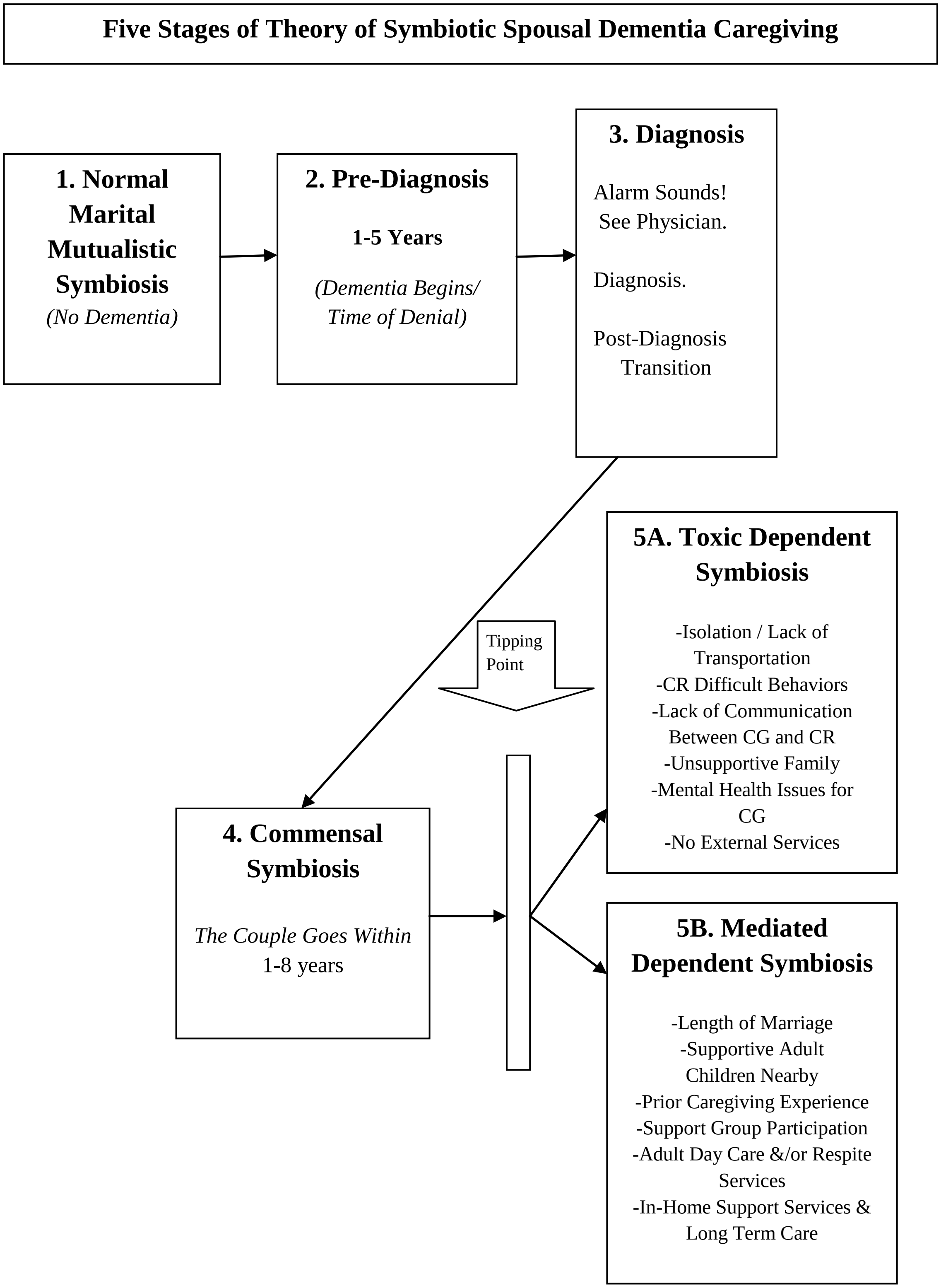
Appendix IV: Sample Atlas.ti Network View

"Factors Contributing to Tipping Point from Commensalistic Symbiosis to Dependent Symbiosis"



Note: This network view shows that there are 11 codes which are related to the Tipping Point. Each has shown to be a cause for reaching the tipping point. Whether I choose to use all 11 in the analysis, depends on their number of times coded.

Appendix V: Figure of Stage Theory of Spousal Dependent Symbiosis



Appendix VI: Demographic Data for 40 Respondents

(1-20)

Name of Respondent	Gender	Age of CG	Race/Ethnicity of CG	Religion	CG Employed
#1 Amy	F	75	White/Irish	Catholic	No
#2 Karen	F	69	White /Irish	Catholic	No
#3 Matt	M	82	White/Jewish	NA	No
#4 Rob	M	65	White	NA	No
#5 Rita	F	64	White / Irish	Catholic	No
#6 Moira	F	67	White /Irish	Catholic	Yes, P/T
#7 Elizabeth	F	79	White / Lithuanian	Jewish	No
#8 Brenda	F	74	White / German	Catholic	No
#9 Judith	F	72	White/Irish	Catholic	Yes
#10 Laura	F	73	White/Greek	NA	No
#11 Maggie	F	59	White/Irish	Catholic	Yes
#12 Sarah	F	75	White	NA	No
#13 Millie	F	78	African American	Baptist	No
#14 Lawrence	M	85	African American	Congrega.	No
#15 Dina	F	65	White/Jewish	Jewish	No
#16 Earl	M	76	Asian /Chinese	NA	No
#17 Will	M	68	White	Catholic	No
#18 Doug	M	75	White/ Irish	NA	No
#19 Kay	F	65	White	NA	No
#20 Annalise	F	68	White/Hungarian	Catholic	Yes

Demographic Data cont.

(21-40)

Name of Respondent	Gender	Age of CG	Race/Ethnicity of CG	Religion	CG Employed
#21 Lena	F	75	White	NA	Yes P/T
#22 Eddie	M	85	White	Presby.	No
#23 Betty	F	78	White	Yes. ?	No
#24 Nora	F	75	White	No	Yes, P/T
#25 Amanda	F	76	White	Methodist	No
#26 Kitty	F	85	White/Italian	Catholic	No
#27 Christina	F	72	White	NA	Yes, P/T
#28 Louise	F	65	White/Italian	Catholic	Yes, until past yr.
#29 Dan	M	78	White	NA	No
#30 Abbie	F	83	White/Italian	Catholic	No
#31 Jill	F	82	White	NA	No
#32 Sue	F	76	White/Russian	NA	No
#33 Martha	F	62	White	Jewish	Yes
#34 Wayne	M	76	White	NA	No
#35 Lucille	F	82	White	Catholic	No
#36 Kieran	M	58	White	NA	Yes
#37 Bella	F	59	White	Catholic	Yes
#38 Grace	F	63	White	Catholic	No
#39 Kathleen	F	33	White	Lutheran	Yes
#40 Phil	M	70	White	Jewish	No

Appendix VII: Table Showing Respondents and Their Medical Interactions

Note: The shaded boxes under negative medical interactions (MI) are the cases considered most extreme.

(1-20)

Name of Respondent	Age of CG	Positive MI	Neutral MI	Negative MI
#1 Amy	75	4	4	2
#2 Karen	69	5	1	1
#3 Matt	82	5	3	0
#4 Rob	65	0	6	0
#5 Rita	64	2	3	8
#6 Moira	67	1	2	5
#7 Elizabeth	79	1	3	2
#8 Brenda	74	1	3	9
#9 Judith	72	1	3	11
#10 Laura	73	1	2	1
#11 Maggie	59	3	3	10
#12 Sarah	75	1	2	0
#13 Millie	78	7	5	2
#14 Lawrence	85	3	1	3
#15 Dina	65	12	8	6
#16 Earl	76	2	0	5
#17 Will	68	7	3	0
#18 Doug	75	2	0	3
#19 Kay	65	2	2	1
#20 Annalise	68	5	2	9

Medical Interactions Table cont.

(21-40)

#21 Lena	75	1	0	1
#22 Eddie	85	1	1	2
#23 Betty	78	0	0	4
#24 Nora	75	6	1	7
#25 Amanda	76	6	0	0
#26 Kitty	85	0	0	1
#27 Christina	72	3	0	3
#28 Louise	65	5	0	1
#29 Dan	78	0	1	2
#30 Abbie	83	4	0	1
#31 Jill	82	6	0	2
#32 Sue	76	2	0	7
#33 Martha	62	5	2	10
#34 Wayne	76	4	1	0
#35 Lucille	82	0	0	1
#36 Kieran	58	1	1	8
#37 Bella	59	4	0	12
#38 Grace	63	3	0	4
#39 Kathleen	33	6	0	6
#40 Phil	70	1	1	0