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The role of family coping styles in psychological adjustment of spouse caregivers to dementia patients

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THE ROLE OF FAMILY COPING STYLES IN PSYCHOLOGICAL ADJUSTMENT OF SPOUSE CAREGIVERS TO DEMENTIA PATIENTS

by

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Abstract

THE ROLE OF FAMILY COPING STYLES IN PSYCHOLOGICAL ADJUSTMENT OF SPOUSE CAREGIVERS TO DEMENTIA PATIENTS

by

S. Deborah Majerovitz

Advisor: Professor Tracey A. Revenson

This study examines the role of family adaptability in moderating the relationship between caregiving stress and negative psychological outcomes among spouses caring for a partner with dementia at home. It also assesses the relationship between adaptability and the role that spouses adopt in relation to the patient (spouse versus caregiver role). The majority of caregiving studies focus on the individual caregiver's response to stress. By examining the relationships among adaptability, marital roles, and psychological adjustment, this study moves beyond the existing research by considering the context in which caregiving takes place -- the ongoing relationship between patient and spouse.

In-person, structured interviews were conducted with fifty-four spouse caregivers. Two types of caregiving stress were considered: hours per day spent caring for the patient and memory and behavior problems. Psychological outcomes included caregiver burden and depression.

Higher levels of memory and behavior problems were related to greater caregiver burden and depression.

Adaptability served as a moderator of the relationship between hours of care and depression, but not burden. For caregivers low in adaptability, spending more hours per day caring for their partner with dementia was related to greater depression. For caregivers high in adaptability, hours of care were unrelated to depression. A similar moderating effect was found for memory and behavior problems, although the interaction was only significant at $p<.10$.

Adaptability was unrelated to spouses' role choice. Instead, spouses caring for a partner with more severe dementia were more likely to endorse a caregiver role, while caregivers for a less impaired partner were more likely to choose a spouse role. However, cluster analysis identified a small subset of caregiving spouses who were caring for a severely demented partner, were below the sample mean in adaptability, and endorsed a spouse role. For these spouses, depression levels were the highest in the sample.

These findings suggest that it is important to consider family coping styles such as adaptability when assessing the impact of caregiving on family members. Implications of these findings for service providers, and suggestions for future research are discussed.

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Advances in medical knowledge and technology are allowing people to live longer than ever before. The media often refer to the "graying of America," or the increasing percentage of the population over the age of 65. Unfortunately, increased longevity does not always mean prolonged physical and mental health. As a result, families are more often faced with extended periods of providing care to an elderly, physically or mentally disabled family member. The severe, chronic stress that these caregivers face has been receiving increasing attention in both the academic literature and popular press.

One group that has been a particular focus of research and intervention are caregivers to people suffering from conditions that cause dementia, such as Alzheimer's disease. Dementia is defined as "a chronic or persistent disorder of the mental processes due to organic brain disease. It is marked by memory disorders, changes in personality, deterioration in personal care, impaired reasoning ability and disorientation" (Laurence Urdang Associates, 1981, pg. 109). Researchers estimate that between 2 million (Light & Lebowitz, 1989) and 4 million (Engler & Goldstein, 1988; National Institute on Aging, 1990) people in the United States have Alzheimer's disease, the most common cause of dementia.

Caring for a relative with dementia is physically and emotionally taxing and can take up most or all of the

caregiver's time. Patients may require constant supervision and extensive assistance with activities of daily living. Many caregivers report spending more than 40 hours per week providing direct care to the patient (Enright, 1991; Ory, Williams, Emr, Lebowitz, Rabins, Salloway, Sluss-Rudbaugh, Wolff, & Zarit, 1985). For many, however, the most difficult part of caregiving lies in the loss of the interaction with the care receiver on an intellectual and emotional level. One daughter described her mother's mental deterioration from Alzheimer's disease as "losing her mind in handfuls" (Roach, 1985, pg. 221).

Despite the constant care and supervision that dementia patients require, the majority of people with dementia live in the community, with family members serving as the primary caregivers (U.S. Dept. of Health and Human Services, 1984). Within families, the spouse (when the patient has one) is most likely to serve as primary caregiver for an elderly, physically or mentally impaired partner (Johnson, 1983).

An extensive research literature documents the negative impact of caring for a mentally or physically impaired relative on the health and psychological well-being of family caregivers in general and spouse caregivers in particular (see Brody, 1989; Cohler, Groves, Borden & Lazarus, 1989; Dillehay & Sandys, 1990; Morris, Morris & Britton, 1988a for reviews of this literature). The overwhelming majority of studies have conceptualized

caregiving within the framework of a standard stress model. They have considered caregiving as the stressor, documented the physical and psychological impact of this stressor on the caregiver, and identified potential moderators of that impact, such as social support or particular coping strategies.

Very little attention has been devoted to the longstanding pattern of interaction between patient and caregiver, despite the fact that most family caregivers have maintained intimate relationships with the patient for most of their adult lives. Many studies make no distinction between different types of caregivers, such as spouses versus children, or caregivers to physically versus mentally impaired patients, despite the very different coping tasks these groups of caregivers face. Another common omission of the caregiving literature is the failure to consider the structure of the relationship between caregiver and patient, both currently and prior to illness onset. This omission is a serious one, as it is the very closeness of the relationship between family members that both motivates them to continue providing care in the face of serious disruptions to their own lives, and makes the deterioration of the patient so painful to watch.

Literature on family systems provides a perspective that is extremely relevant to research on the dementia family caregiver. When studying a stress to the family,

systems theorists believe that it is not enough to simply focus on the stressor and the responses of those family members most directly affected. Instead, they believe it is essential to consider established patterns of family interaction that affect families' interpretation of the problem, both individually and as a group, as well as their response to it (Walsh, 1982). From this perspective, no study of caregiving would be complete without an evaluation of families' characteristic patterns of coping with stress.

One aspect of family coping derived from the family systems literature that is particularly relevant in times of stress is family adaptability (Olson, 1986, 1991a,b; Olson, Portner & Lavee, 1985; Olson, Russell & Sprenkle, 1983). Adaptability is defined as "the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress" (Olson et al., 1983, pg. 70). More adaptable couples would be expected to share more decision-making and leadership tasks than less adaptable couples, to have more variability in their division of labor, and to be more likely to change their relationship rules or expectations of one another. When facing a stressor or challenge, such as dementia, the willingness of each member of a couple to change the organization or role structure of the relationship should affect the nature of his or her response to the stressor

(Olson, 1991b).

Research Aims

The existing caregiving literature focusses on the stresses of caregiving and the distress or burden that caregivers experience as a result. Research has not adequately considered the structure of the existing relationship between patients and caregivers, and how it might relate to spouses' experience of caregiver burden. This study addresses this gap in the caregiving literature. Looking exclusively at spouses caring for a partner with dementia, this study evaluates the role of adaptability in spouses' approach to coping with the extraordinary stress of dementia. The study examines the relationship between spouses' reports of their family's level of adaptability prior to the onset of dementia, the role caregiving spouses adopt in relation to the patient, and predictors of caregiver distress.

The literature review that follows covers three areas. It begins by examining the actual stressors that caregivers face, and the ways in which families allocate caregiving tasks and resources. Next, it reviews literature on predictors of caregiver burden, both among caregivers in general, and caregiving spouses in particular. Finally, it considers the construct of family adaptability, and how this aspect of family coping style may be useful in understanding predictors of caregiver distress. In order to avoid

confusion, the partner with dementia will be referred to as the "patient" and the caregiving partner as the "caregiver" or "caregiving spouse."

Literature Review

The nature of the stressor

The most common cause of dementia is believed to be Alzheimer's disease, a chronic illness characterized by a progressive deterioration of the brain tissue (Mace & Rabins, 1981). The decline in mental capacity associated with Alzheimer's disease becomes gradually but steadily worse over the course of the disease, until patients are completely incapable of self care or of being left alone. The initial symptoms of the disease, memory impairment and a decline in intellectual abilities such as learning or abstract reasoning, are often imperceptible to others. Changes in behavior and mood resulting from patients' concern over these cognitive deficits may be the first symptoms that family members notice (Mace & Rabins, 1981; Ware & Carper, 1982). As the disease progresses, patients' cognitive and memory deficits become more severe and obvious. Wandering, inappropriate or aggressive behavior, and night wakefulness are common problems. Eventually, patients will become extremely confused and disoriented, experiencing impaired physical coordination and incontinence. In the final stages of the disease, patients lapse into a coma. This slow but progressive deterioration

of the brain is always fatal. The course of the disease averages 7 to 10 years, but patients may live with Alzheimer's disease anywhere from 3 to 15 years (Mace & Rabins, 1981).

It is impossible to make a definitive diagnosis of Alzheimer's disease without analyzing a sample of brain tissue. Therefore, diagnoses are made based upon the clinical manifestations of the disorder and elimination of other potential causes of dementia (Albert, 1984; Mace & Rabins, 1981; Mohs & Davis, 1987). A complete medical evaluation is essential to rule out any reversible causes of dementia symptoms, such as depression, metabolic disturbance, or adverse reaction to medication.

The second most common cause of dementia is multi-infarct disease, the death of multiple areas of brain tissue resulting from inadequate blood flow (Mace & Rabins, 1981). A diagnosis of multi-infarct dementia can often be made when dementia is accompanied by a history of cardiovascular disease. In some cases, the patient may be suffering from a combination of the two disorders. Alzheimer's disease alone is believed to be the cause of approximately 50% of dementia cases, with 20% caused by multi-infarct disease, 20% a combination of the two disorders, and the remaining 10% caused by other acute or chronic conditions (Mace & Rabins, 1981). Because it is generally impossible to determine the exact cause of chronic dementia with certainty,

practitioners and researchers often refer to "Alzheimer's disease and related disorders," or "dementia of the Alzheimer type." Therefore, this literature review will refer to the symptoms of dementia, rather than the specific disease process causing them. If a particular study was limited to patients with a diagnosis of probable Alzheimer's disease, the term Alzheimer's disease will be used.

Alzheimer's disease is most prevalent among those aged 65 or older, and becomes increasingly common with more advanced age, although it does occur very rarely in adults in their 40's or 50's (Evans, 1990; Mace & Rabins, 1981). The prevalence of dementia in the population over 65 years of age may be as high as 10.3%, rising to 47.2% among people over 85 (Biegel, Sales, & Schulz, 1991). The disease is twice as common among women as men (National Institute on Aging, 1990), although it must be kept in mind that the disease is most prevalent in advanced age, and that women live longer than men.

Who are dementia caregivers?

Families generally do not share the burden of caring for an impaired relative. Instead, they utilize "serial substitution," where one family member cares for the impaired person alone. When that individual is no longer able, another family member takes over (Cantor, 1983; Johnson, 1983). When there is a spouse available, he or she is most likely to be the primary caregiver. When no spouse

is available, adult children are the most likely to serve as primary caregiver. Among adult children, women (daughters or daughters-in-law) are more likely to serve as primary caregiver than men (Brody, 1981). Spouses tend to provide the most comprehensive care to dementia patients, report less conflict with the care recipient, and are less likely to institutionalize the patient than adult children or other relatives (Colerick & George, 1986; Johnson, 1983; Johnson & Catalano, 1983; Lieberman & Kramer, 1991; Soldo & Myllyluoma, 1983).

The burden of caregiving

Providing care to someone who requires extensive assistance with personal care and who may be resistant to that care as a result of cognitive impairment is physically as well as emotionally taxing. In addition, the costs of care place many caregivers under financial strain. Family caregivers often experience disruptions in their social and family lives, as much of their time must be devoted to caregiving tasks. Some devote more than 40 hours per week to caregiving activities (Ory et al., 1985); in one study of caregivers to brain-injured patients (including Alzheimer's disease), caregivers reported spending an average of 89 hours per week in caregiving activities (Enright, 1991).

The negative impact of caregiving responsibilities is generally referred to in the literature as caregiver burden

(Zarit, Reever, & Bach-Peterson, 1980). A large body of research literature documents the burden experienced by family caregivers, as well as factors which may serve to alleviate it, such as effective coping strategies, social support or professional interventions (Gwyther & George, 1986). Research in this area began in Great Britain in the 1960's, studying the effects of caregiving on families of discharged psychiatric patients (Grad & Sainsbury, 1963; Montgomery, Gonyea, Hooyman, 1985). Subsequent work by gerontologists has built upon these early studies, focussing on family caregivers to the frail elderly and to those suffering from dementia.

Although the literature on caregiver burden is quite extensive, many of the studies suffer from a number of methodological limitations (Barer & Johnson, 1990; Dillehay & Sandys, 1990). The scales used to measure caregiver burden and well-being are inconsistent across studies, making comparison of findings difficult. Many studies fail to differentiate between patients suffering from physical and mental impairments, despite the fact that demands upon caregivers to these two types of patients are quite different. Caregivers to physically-impaired patients face the difficulties inherent in providing physical assistance to patients and concern for patients' health and well-being. Caregivers to mentally impaired patients must also come to terms with the loss of emotional support and companionship

from the impaired person. They must cope with behavior problems and provide supervision to prevent wandering or dangerous behavior. Some studies do not differentiate among spouses, adult children and other relatives, or even between caregivers who live with the patient and those who provide more limited assistance while maintaining a separate residence.

The literature review that follows cites studies that attempt to overcome these methodological limitations whenever possible and primarily includes studies of caregivers to mentally impaired patients. Studies of caregivers to physically-impaired patients, or studies which include both types of caregivers, will be included only when they raise issues that are also relevant to dementia caregivers. When a study was limited to one caregiving relationship, such as spouses or adult children, this will be noted.

Serious disruptions in work and social activities, and extreme fatigue are commonly-cited problems for caregivers (Brody, Kleban, Johnsen, Hoffman, & Schoonover, 1987; Chenoweth & Spencer, 1986; George & Gwyther, 1986; Haley, Levine, Brown, Berry & Hughes, 1987; Rabins, Mace, & Lucas, 1982; Sanford, 1975). Studies have also shown that caregivers find patients' bizarre or aggressive behavior and incontinence to be especially difficult to cope with (Morris et al., 1988a; Rabins et al., 1982; Sanford, 1975).

The various stressors that family caregivers face are likely to affect individual caregivers quite differently. Lazarus and Folkman (1984) conceptualize stress as an interaction between characteristics of the individual and of the environment. In order for an event to cause stress, individuals must appraise that event as stressful, i.e., having the potential to cause harm or loss, or to challenge their capacity to deal with the situation. Different individuals also may find different aspects of the same situation stressful.

Research on the impact of caring for a family member with dementia generally reflects such an interactive theory of stress. The level of stress experienced by caregivers, or the predictors of distress resulting from caregiving, are not consistent across caregivers or across studies, suggesting that individuals react to this situation in very different ways.

Despite this variability among individual caregivers, one finding that is consistent across studies is that caregiving is stressful. Research comparing caregivers to non-caregivers of the same age has affirmed the negative impact of caregiving on family members' lives. Caregivers experience greater degrees of psychological disturbance, lower life satisfaction, and more limited social activities than do non-caregivers of the same age (George & Gwyther, 1986; Haley et al., 1987). Caregivers also report higher

rates of physical symptoms, psychological distress and use of psychotropic drugs than general population norms (Pruchno & Potashnik, 1989). Caregiving spouses have been shown to experience lower levels of immunity and higher rates of infectious disease and depression than non-caregivers matched for age, sex and education (Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991). A similarly matched sample of adult-child caregivers showed higher levels of depression and anxiety disorders than non-caregivers (Dura, Stukenberg, & Kiecolt-Glaser, 1991).

One study of elderly couples comparing respondents caring for a demented spouse to non-caregivers did not find significantly higher rates of anxiety, depression or symptoms of psychiatric disturbance among caregivers (Eagles, Beattie, Blackwood, Restall, & Ashcroft, 1987). Participants in this study were recruited from among all patients registered with a general medical practice in Scotland. The authors suggest that their findings may differ from the overwhelming majority of studies of caregivers because participants were representative of an entire community, rather than those who sought help for problems related to caregiving or responded to advertising for a caregiving study. However, substantial levels of caregiver burden have been noted in another study that randomly sampled an entire population of elderly people (Deimling & Bass, 1986; Poulshock & Deimling, 1984). This

suggests that the elevated levels of burden reported in the majority of caregiving studies cannot be attributed exclusively to their sampling of help-seeking populations, but rather reflect the stresses of caregiving.

Recent research differentiates between more objective aspects of caregiving stress such as patients' behavioral problems or the level of assistance needed with activities of daily living (ADL), and subjective aspects of stress such as caregivers' perceptions of these factors as stressful. Zarit and his colleagues (Zarit et al., 1980) found that the severity of patient impairment was unrelated to the level of caregiver burden. Other studies report similar findings (e.g. Fitting, Rabins, Lucas & Eastham, 1986). Morycz (1985) found that caregivers' perception of caregiving as stressful was a better predictor of the desire to institutionalize patients than patients' actual level of impairment. Similarly, caregivers' subjective level of stress and their relationship to the patient (child vs. spouse) were better predictors of the decision to institutionalize than patients' actual level of impairment in a study of 321 caregiving families (Lieberman & Kramer, 1991).

The majority of studies, however, have documented a relationship between patients' level of physical and mental impairment and caregiver burden (Biegel et al., 1991). Poulshock and Deimling (1984) conceptualized burden as a

multidimensional construct involving caregivers' personal responses to specific caregiving tasks and the impact of those tasks on caregivers' lives. They drew a distinction between the impact of mental and physical impairment, and found that these different types of burden seemed to affect caregivers' lives in different ways. Mental impairment was most strongly related to strain on family relationships, whereas the burden of physical impairment had its strongest relationship with restrictions in caregivers' activities. In another study of Alzheimer's caregivers, higher levels of behavioral problems were related to greater caregiver depression, while patient's functional impairment was unrelated to depression (Schulz & Williamson, 1991). Poulshock and Deimling further suggest that other research (e.g., Zarit et al., 1980) may have found little relationship between patients' actual level of impairment and caregiver burden because burden was measured as a unidimensional construct.

Research with caregivers to both physically and mentally impaired elders provides further evidence for the differential effects of mental and physical impairment on caregiver distress. In one study (Deimling & Bass, 1986), path analysis showed that elderly care recipients' level of physical impairment had a direct effect on caregiver stress, whereas cognitive impairment had only an indirect effect. Elders with greater levels of cognitive impairment exhibited

more disruptive behaviors and poorer social functioning which, in turn, had a direct impact on caregiver stress. In another study of daughters and daughters-in-law living with an elderly parent, however, there were no differences in mental or physical health between caregivers to mentally-impaired, functionally-impaired, or healthy elders (Cattanach & Kraemer Tebes, 1991). These authors suggest that the similarities in life circumstances among caregivers in their sample (all were daughters or daughters-in-law) may have been more important predictors of mental and physical health outcomes than elders' functional status.

In addition to differential effects of physical and mental impairment on caregivers' well-being, there is some evidence that caregivers' personality traits may affect their response to the stresses of caregiving. Neuroticism was directly related to higher perceived stress and poorer mental and physical health in a sample of 51 spouse caregivers (Hooker, Monahan, Shifren, & Hutchinson, 1992), and indirectly related to health outcomes through its relationship with perceived stress. Optimism was also related to perceived stress and mental health, but not to physical health.

In another study examining personality traits that spouse and adult child caregivers bring to the caregiving situation, both relationship orientation and the quality of the relationship between caregiver and patient prior to

illness onset were related to caregiver depression (Williamson & Schulz, 1990). Caregivers with higher levels of communal orientation (concern for the needs of others and feelings of responsibility for meeting those needs) experienced lower levels of depressive symptoms than those lower in communal orientation. Furthermore, the predictors of depression were different for men and women. For men, depression was highest for those who had lower levels of communal orientation and were not close to the patient prior to illness onset. For women, greater depression was related to high communal orientation and greater closeness.

Other research suggests that patients' level of impairment and caregivers' personal resources each play a role in predicting caregiver burden. A longitudinal study of spouse caregivers to patients with dementia (Vitaliano, Russo, Young, Teri & Maiuro, 1991) found that patients' level of impairment in performing activities of daily living, caregivers' vulnerability to stress (anxiety, anger, poor physical health) and initial levels of caregiver burden were all independent predictors of greater burden 15-18 months later. Higher levels of personal resources (social support, positive outlook) predicted lower caregiver burden. In addition, caregivers with higher initial levels of vulnerability (anger and poor health) coupled with lower levels of resources (social support and positive outlook) were more burdened at follow-up than caregivers with either

low resources or high vulnerability alone. These findings are particularly relevant to Lazarus and Folkman's (1984) conceptualization of adaptation to stress. Understanding the stressor alone is not enough to predict individual responses to that stressor. Rather, it is the interaction of resources, vulnerability, and individual responses to the stressor that determine adjustment to stress.

Other longitudinal research with caregivers to spouses with dementia (Zarit, Todd, & Zarit, 1986) provides insight into changes in the impact of the illness over time. Spouses caring for less mentally-impaired patients experienced higher levels of caregiver burden two years after an initial interview. The authors suggest that this finding may reflect the course of Alzheimer's disease; although patients' functional capacity deteriorates steadily as the disease progresses, distressing behaviors such as restlessness, wandering and paranoia also decrease and eventually subside as the patient is less able to take initiative or communicate (Haley & Pardo, 1989). This change may actually lessen the physical strain of caregiving as patients are less resistant to care and no longer require constant supervision. Thus, the higher absolute levels of burden among caregivers to less mentally-impaired patients may be a function of more frequent behavioral problems.

Another study of spouse caregivers (Pruchno & Resch, 1989) offers further evidence for a decrease in behavioral

problems as physical impairment worsens. Memory impairment showed a curvilinear relationship to caregiver burden: caregivers to patients with the lowest and highest levels of memory impairment experienced less caregiver burden than caregivers to moderately impaired patients. This lends further support to the hypothesis that the nature of caregiving tasks change, and may actually become less taxing on caregivers, as cognitive impairment progresses. These findings highlight the changing needs of dementia caregivers over time and the dynamic nature of the caregiving role as the illness progresses.

To summarize, the concept of caregiver burden is multidimensional, including actual caregiving tasks, patients' level of physical and mental impairment, behavioral problems, lifestyle changes necessitated by caregiving, and caregivers' subjective evaluation of all these as stressful. Behavioral problems such as aggression or night wakefulness, and incontinence seem to be most difficult for family members (Biegel et al., 1991; Chenoweth & Spencer, 1986; Rabins et al., 1982). There is some evidence that caregivers' perception of these problems as stressful is more strongly related to feelings of burden than the severity of the problems themselves, although this finding is not consistent across studies. Caregivers' personality traits and personal resources may affect both caregivers' appraisal of the situation as stressful and

their ability to cope with the stresses of caregiving. Furthermore, patients' physical and mental impairments may be related to different psychological and health outcomes. The stressors associated with caregiving, and caregivers' capacity to cope with those stressors, may change over the course of the illness. And finally, when caregivers are compared to non-caregivers of the same age, there is ample evidence that caregivers truly are burdened, experiencing greater levels of distress.

The unique situation of spouse caregivers.

Spouse caregivers face a number of unique stressors in addition to those faced by other family members. First, as dementia primarily strikes those over 65, spouse caregivers are older and often in poor health themselves (Chenoweth & Spencer, 1986), making the physical demands of caregiving more difficult to carry out. Barusch (1988) found that a majority of elderly spouse caregivers worried about what should happen to both patient and spouse if the caregiver also fell ill, feelings of depression, and the physical difficulty of caregiving.

Second, spouse caregivers are faced with serious losses of social support. It is common for couples to socialize primarily with other couples (Mace & Rabins, 1981). When one spouse becomes impaired, the other is perceived socially as a single person and can be excluded from an established social circle. However, the spouse of a dementia patient is

not truly single, making it even more difficult to find a social niche (Chenoweth & Spencer, 1986; Mace & Rabins, 1981). For caregivers who leave their jobs, this social outlet is eliminated as well (Chenoweth & Spencer, 1986).

In addition to decreased support from the social network, caregiving spouses also face the loss of their primary source of love and support, their spouse, as mental deterioration progresses (Mace & Rabins, 1981). For most older couples, irrespective of the quality of the marital relationship, the spouse is the person with whom they have spent most of their adult lives. In fact, 88% of elderly spouse caregivers in a qualitative study of caregivers' experiences (Barusch, 1988) cited "missing how the impaired spouse once was" as a major problem. In another study asking spouse caregivers about levels of intimacy before and after the onset of dementia (Morris, Morris & Britton, 1988b), spouses who reported a greater loss of intimacy following the onset of dementia also reported higher levels of depression.

Spouse caregivers also experience changes in long-established gender role functions within the relationship (Mace & Rabins, 1981). If a couple has maintained traditional gender roles within their relationship, learning new tasks, such as housekeeping for husbands or financial management for wives, can be extremely difficult.

Several studies have shown that wives experience

greater caregiver burden and depressive symptoms than husbands (Barusch & Spaid, 1989; Fitting et al., 1986; Harper & Lund, 1990; Ory et al., 1985). This may be because men are more willing to seek outside help with the practical aspects of caregiving, whereas women are more likely to attempt to manage on their own (Ory et al., 1985). In a longitudinal study (Zarit et al., 1986) wives experienced greater caregiver burden than husbands at the time of an initial interview, but two years later, burden scores were equivalent for both husbands and wives. Schulz & Williamson (1991) reported similar gender differences in depression in their two-year longitudinal study. With time, wives may become more comfortable accepting assistance with caregiving tasks, thereby diminishing their level of burden (Zarit et al., 1986). It is also possible that these gender differences simply reflect men's reluctance to report symptoms of distress, or the more general tendency for women to report higher levels of depressive symptoms than men (Barusch & Spaid, 1989), although this does not fully explain why men report similar levels of burden to women later in their caregiving careers.

Some evidence to the contrary is provided by a national survey of male caregivers (Kaye, Applegate & Jacobs, 1989), in which men reported a low level of reliance on formal, paid services. A recent meta-analysis of 14 studies (Miller & Cafasso, 1992) concluded that although women perform more

personal care activities and household chores for impaired elders than men do and experience higher levels of caregiver burden, the magnitude of gender differences among caregivers was actually quite small.

Other research comparing husband and wife caregivers has found different predictors of depression for men and women (Eagles et al., 1987; Moritz, Kasl, & Berkman, 1989). In contrast to research finding greater distress among wives, these two studies found that greater cognitive impairment in patients was related to greater depressive symptomology for caregiving husbands, but not for caregiving wives. Moritz and her colleagues (1989) point out that a greater negative impact of caregiving for men is consistent with research showing the greater negative impact of widowhood on men, and the apparent benefits of marriage for men's mental health.

Although spouse caregivers seem to face more potential stressors than other caregivers, research comparing spouse and adult-child caregivers does not always provide clear evidence of greater burden among spouse caregivers. Zarit et al. (1980) found no difference between spouses and adult children in the level of caregiver burden experienced. However, George and Gwyther (1986) found that spouses suffered from greater stress and lower life satisfaction, made more visits to the doctor and rated their own health as poorer than other family caregivers, even after controlling

for the more advanced age of the spouse caregivers. Spouses also had significantly lower incomes than other caregivers. Cantor (1983), too, found greater distress among spouses than adult children in a study of caregivers to frail elders. However, not all caregivers in this study lived with the impaired elder; greater distress among spouse caregivers may have been related to the fact that children were much less likely to be living with the care recipient.

Despite the fact that family caregivers have maintained a lifelong relationship with the patient, few studies have considered the structure or quality of this ongoing relationship. Research that has addressed this issue provides evidence that the relationship between caregiver and patient prior to illness onset is related to subsequent caregiver well-being. In two studies of spouse caregivers to dementia patients, spouses who report having had a closer relationship with the patient prior to illness onset experience less distress and burden (Morris et al., 1988b; Robinson, 1990). In Williamson & Schulz's (1990) study, a closer relationship prior to illness onset was related to lower caregiver burden, but not to depression, among spouse and adult child caregivers. Other research has found no association between the quality of the relationship prior to illness onset and levels of caregiver well-being (Gilhooly, 1984).

In all of these studies, relationship closeness was

assessed retrospectively, considering the relationship between caregiver and patient prior to illness onset. While this is an unavoidable methodological limitation in this type of research, as participants can only be identified for inclusion in the research once they become caregivers, it must be considered in interpreting the findings. It is possible, for example, that caregivers who experience better psychological adaptation to caregiving recall their prior relationship more fondly than those who are currently overwhelmed by the burdens of care. Still, these findings do emphasize the importance of continued research on the relationship between pre-existing patterns of interaction between caregiver and patient and caregivers' psychosocial adaptation to the stresses of caregiving. This type of research is especially important for understanding psychological adjustment among spouse caregivers, for whom caregiving takes place in the context of their primary supportive relationship.

Summarizing what is known, spouse caregivers provide the most comprehensive and consistent care to dementia patients of all family caregivers. Spouses tend to be the oldest caregivers and may be in ill health themselves, or experience greater financial difficulties than other caregivers. They also experience a loss of support, both from their social network and, more important, from the demented spouse. This combination of high stress and

reduced support may make spouse caregivers particularly vulnerable to psychological distress.

Wives may experience greater distress than husbands, although differences are of small to moderate magnitude, and different aspects of the caregiving experience may predict burden for men and women. There is some evidence that greater loss of intimacy is related to higher levels of burden, and that a closer relationship prior to illness onset is related to lower caregiver burden.

The construct of family adaptability

Although the literature on predictors of caregiver burden is extensive, the results of these studies are far from conclusive. Research incorporating the complex relationship between patient and caregiver into the stress-distress equation may help to clarify some of the inconsistencies in past studies. Family systems theory provides a framework for formulating questions about the structure and quality of the spousal relationship and the role this structure may play in spouses' adaptation to caregiving.

Family systems theorists view the family as an interactive unit, in which each person acts according to a set of family rules and established patterns of interaction, with the behavior of each family member affecting the responses of the others (Walsh, 1982). When one family member presents a challenge to established interaction

patterns, the family may interpret the unusual behavior as problematic and try to change the behavior with a view toward reintegrating this individual into the established system. Or, they may slowly adapt their family system to accommodate the change.

Family systems theorists refer to this tendency of families to change in response to situational stressors as adaptability. The construct of adaptability is defined as "the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress" (Olson et al., 1983, page 70). Adaptability is particularly relevant in the study of dementia caregivers, as families must drastically alter established role relationships and adapt to extreme stress.

Theory and research on family-level coping and the notion of family adaptability is based in large part on Hill's ABC-X model of family adjustment (Hill, 1949). This model views the crisis to the family created by a stressful event (X) as a function of the event itself (A), the family's resources to deal with the event (B) and the family's definition of the event (C). In many respects, this approach is consistent with Lazarus and Folkman's (1984) model of individual-level coping. Both approaches assume that in order to understand stress responses, it is necessary to consider not only the stressor itself, but also

the meaning of that stressor for those affected and the resources available (or perceived to be available) to deal with the situation. What family-systems theorists add to Lazarus' model is the need to consider the reciprocal effects of each family member's response to the stressor on other family members and on the family as a unit.

If family resources are adequate to adapt to the stressful situation, a family crisis can be avoided. This adaptation may involve making changes in the way problems are usually dealt with, or broader changes in the family's organizational structure or in the expectations family members hold for one another. When families are unable to make these changes, or their efforts at adaptation are inadequate, a "crisis" occurs. The family's normal functioning is disrupted, leading to distress for one or more family members (McCubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980).

There is some disagreement among family systems theorists in the conceptualization of adaptability, and in the level of change that will maintain optimal family functioning. The Circumplex Model of family functioning (Olson et al., 1983; Olson et al., 1985; Olson, 1986) proposes that well-functioning families will differ in the degree of adaptability they prefer in their day-to-day lives. Some families employ a less adaptable approach (called "structured" in the model), in which overall

consistency is maintained in family roles, performing household chores, and approaching problems or novel situations. Other families utilize a more adaptable style (called "flexible"), changing their approach to problems and shifting household tasks or leadership roles from person to person as the situation changes. For example, a less adaptable family would assign particular household chores to each family member and expect them to be carried out by the person assigned to them, even if that person had a conflicting responsibility. If the wife were assigned the chore of cooking dinner each night, then she would be expected to prepare dinner even on days when she had to work late. In contrast, chore assignments would be more flexible in more adaptable couples, so that dinner might always be prepared by the partner that arrived home first.

According to the Circumplex Model, neither style is considered better, but simply different. Only families at the extremes of the continuum -- families that live without any type of structure (called "chaotic") or that are completely unable to adapt to new situations (called "rigid") -- will experience problems.

Other family systems theorists (Beavers & Voeller, 1983) argue that there is a linear relationship between adaptability and family adjustment, such that greater adaptability is always related to greater family well-being, as more adaptable families exhibit greater capacity to

change in the face of situational challenges. Research on the relationship between family adaptability and family adjustment has yielded mixed results. Studies of families of schizophrenics, criminal offenders, or couples who have sought therapy for marital problems have supported the Circumplex Model, reporting a higher concentration of families who are at the extremes of adaptability (Olson, 1986). Other studies found either a linear relationship between family adaptability and positive family functioning, or no relationship (Green, Harris, Forte, & Robinson, 1991a,b; Green, Kolevzon, & Vosler, 1985; Olson, 1991a).

Two studies have applied the Circumplex Model, including the construct of family adaptability, to spouse caregivers for people with Alzheimer's disease. In an unpublished dissertation, Bowers (1990) hypothesized that family adaptability and family cohesion (a construct also included in the Circumplex Model reflecting the closeness or interconnectedness of family members) would predict the role that spouses adopted in relation to their partner with dementia. She also hypothesized that the choice of a role reflecting more extreme levels of adaptability and cohesion would be related to higher levels of caregiver burden than the choice of a role reflecting more moderate levels of adaptability and cohesion. However, neither caregiver role nor family adaptability scores were related to spouses' level of caregiver burden.

A second study considered family adaptability as a potential coping resource among 121 spouse and adult child caregivers (Rankin, Haut, & Keefover, 1992). Marital role adaptability, cohesion and communication were all related to lower levels of depressive symptoms and higher levels of family satisfaction for caregivers. For spouse caregivers, these measures assessed the adaptability, cohesion, and communication in their relationship with the patient, whereas for adult children, the relationship with their own healthy spouse was assessed. Thus, the study was inconsistent in its assessment of relationship resources across study participants.

To summarize, studies utilizing the construct of adaptability as a potential predictor of family functioning or adaptation to a major stressor have had only limited success. While there is some evidence in the family systems literature that highly dysfunctional families may be overrepresented at the extremes of adaptability (Green et al., 1985; Olson, 1986), this finding is not consistent across studies. Among families that do not exhibit signs of dysfunction or distress, there does not seem to be a direct relationship between adaptability and family adjustment (Green et al., 1991).

Unfortunately, the two studies assessing the relationship between family adaptability and caregiver burden in the experience of caregivers to dementia patients

are characterized by serious methodological inconsistencies. Bowers (1990) utilized an idiosyncratic method of conceptualizing adaptability by relating it to the choice of certain marital roles, while Rankin and colleagues' (1992) research did not provide parallel information on caregivers' relationships with care receivers. Thus, the role of adaptability in predicting adjustment to caregiving remains essentially untested in this population.

Reconceptualizing the role of adaptability in adaptation to stress

Despite the debate among family systems theorists regarding the best way to conceptualize adaptability in healthy, well-functioning families, there is consensus on the importance of the construct of adaptability for understanding family interaction (Green et al., 1985). Conceptually, adaptability denotes the tendency to adapt family roles in response to situational changes. Using this definition, one might expect that when faced with an illness such as dementia that drastically alters the patient's ability to fulfill his or her existing family roles, more adaptable spouses would experience lower levels of caregiver burden.

There is another possible way to conceptualize the relationship between adaptability and caregiver well-being that might account for the inconsistent findings in the literature. Among samples of families experiencing clinical

pathology, extremes of adaptability (inability to change or inability to maintain some type of family organization) were reported (Olson, 1986). However, the range of adaptability levels found in the majority of families were not associated with positive or negative family adjustment in a consistent manner. This is not to say that adaptability is only important in its extremes. Instead, among well-functioning families, adaptability may serve as a moderator of the relationship between stress and well-being.

Utilizing Lazarus and Folkman's (1984) stress and coping paradigm, adaptability may affect the way in which individuals appraise a stressful situation, specifically, those aspects of the situation that tax their coping resources. Conceptualizing adaptability in this way, one might predict that when one spouse develops dementia, more adaptable spouses will be able to alter the established patterns of interaction and rules within their relationship to accommodate patients' diminished functional capacity. This would involve changing the demands of the spouse role in order to maintain a marital type relationship despite the patient's deficits. For example, providing emotional support is one of the many things spouses do for one another. Dementia patients may no longer be able to listen, problem-solve, or offer reassurance. However, they may still be capable of showing a sense of caring and concern that also provides a form of emotional support. Maintaining

a marital relationship will become more difficult as patients' mental deterioration progresses. Following this line of reasoning, more adaptable spouses would be more likely to make changes in their expectations of the marital role in an effort to maintain a marital-type relationship despite the patient's dementia. If this were the case, signs of patients' mental deterioration would represent the failure of spouses' efforts to adapt the marital role, and would thus represent the greatest source of caregiver burden.

In contrast, less adaptable spouses may be less likely to change their existing role structure to accommodate patients' cognitive impairment. Unable to continue functioning in a spouse role, patients will be assigned a sick role, one in which individuals are excused of their usual role responsibilities as a result of illness (Parsons, 1951). The sick role is outside the scope of normal family roles, as patients are not contributing to the needs of the family, and family members are responsible for the patient's care. Once the dementia patient is assigned the sick role, the healthy spouse adopts the role of caregiver, and interaction between the spouses is centered primarily around caregiving tasks. Thus, the practical demands and time constraints of caregiving should represent the primary source of caregiver burden for less adaptable spouses.

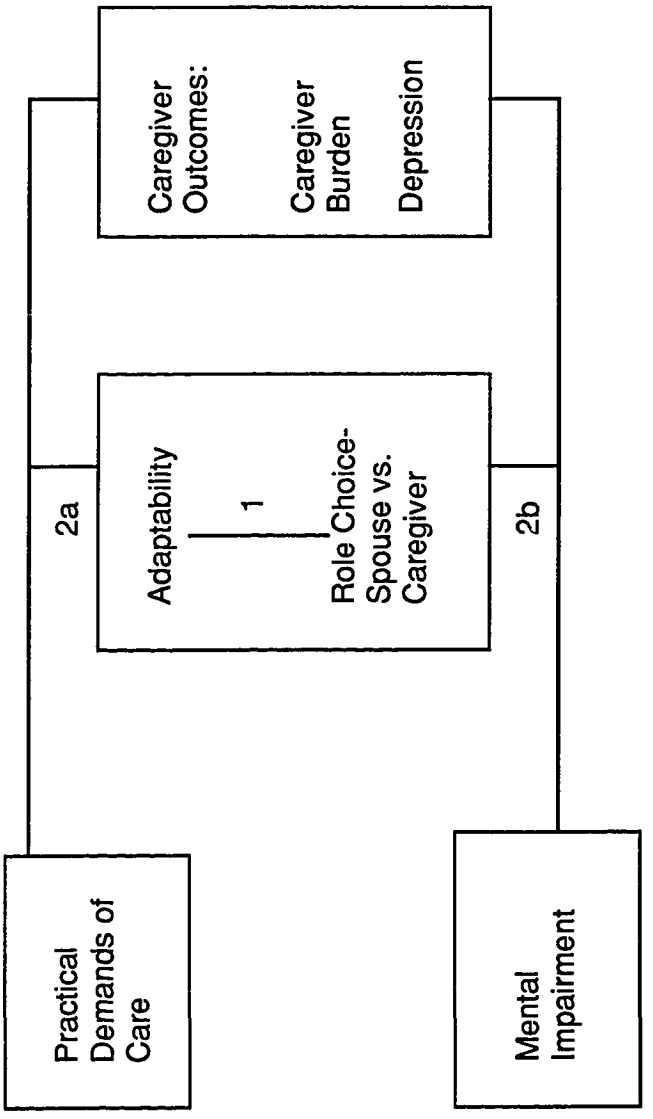
If these hypothesized differences between more and less

adaptable caregivers do exist, then different aspects of living with a spouse with dementia will be perceived as more stressful and ultimately lead to psychological distress. For more adaptable caregivers, distress would arise when patients' mental deterioration was more severe, limiting the success of their efforts to adapt the marital role to accommodate their partners' limitations. For less adaptable caregivers, distress would be related to practical caregiving demands such as time spent caring for the patient. It is not hypothesized that adaptability will be related to level of distress, but rather that different aspects of the situation will be related to greater distress for more and less adaptable caregivers.

This dissertation tests this alternative conceptualization of adaptability. Rather than simply assessing the direct relationship between adaptability and well-being, the study also tests the hypothesis that family adaptability serves as a moderator of the relationship between caregiving stress and caregivers' psychological well-being: specifically, the predictors of burden and depression will differ for caregivers at different levels of adaptability. It also tests the hypothesis that level of family adaptability will affect the role that the healthy spouse adopts in relation to the patient. The theoretical model describing these relationships is depicted in Figure 1.

Figure 1

Conceptual model for the research



Study Hypotheses

1. Caregiving spouses with less adaptable coping styles will tend to view the dementia patient in a sick role and adopt a caregiver role in relation to the patient. In contrast, caregiving spouses with more adaptable styles should continue to see the dementia patient in a spouse role, albeit in an altered capacity. Therefore, they will adopt a spouse role for themselves in relation to the patient. This is represented by line 1 in the conceptual model.

2. Instead of a direct relationship between adaptability and caregiver outcomes, adaptability will moderate the relationship between characteristics of patients' illness and caregiver outcomes. This is represented by lines 2a and 2b in the conceptual model. (This hypothesis implies that no differences are expected between more or less adaptable spouses, or between spouses who adopt a spouse or caregiver role, in absolute level of depression or feelings of caregiver burden.)

For less adaptable individuals, the focus of the marital interaction will be on the practical demands of care. For these caregiving spouses, depression and feelings of burden will be greater when more time is spent in caregiving tasks. Patients' level of memory impairment and behavioral problems will not prove to be as strong a predictor of burden for these caregivers. This relationship

is represented by line 2a in the conceptual model. In contrast, for more adaptable caregiving spouses, the stress of patients' mental and behavioral impairment will be the strongest predictor of psychological distress and feelings of burden. This relationship is represented by line 2b in the conceptual model.

Methods

Sample and procedures

In-person, structured interviews were conducted with 54 spouses who are the primary caregiver for a partner suffering from chronic dementia. Interviews lasted approximately one hour and the majority were conducted in caregivers' homes by the principal investigator (48) or by a research assistant (6).

Participants were recruited from the following sources in the five boroughs of New York City and the surrounding metropolitan area (Nassau, Suffolk and Westchester Counties and Northern New Jersey): caregiver support groups and supportive programs sponsored by the Alzheimer's disease and Related Disorders Association, the Long Island Alzheimer's Foundation, and various smaller agencies; caregiver educational meetings sponsored by the Alzheimer's Association; adult day care programs; dementia respite programs; private professional practices (3 physicians, 2 neurologists, 1 neuropsychologist and 1 social worker); and newspaper advertising.

Recruitment procedures varied to accommodate the needs of the various agencies and professional practices. In most cases, flyers describing the study were sent to the sponsoring agencies or practices, which distributed them during group meetings, included them in regular mailings to members, or mailed them individually. Spouses interested in participating would then contact the principal investigator to arrange an interview. When flyers were distributed in person by group leaders or were included in a large mailing, participants were asked to call a telephone number listed on the flyer for further information about the study or to set up an interview. When flyers were mailed individually, pre-addressed, stamped postcards were included for caregivers to return if they would like to set up an interview or receive further information. At educational meetings and some support groups, the principal investigator addressed the group directly and distributed flyers to participants. In the case of one medical group practice and one support program, the principal investigator called spouse caregivers directly to invite them to participate. As the actual number of program participants who received flyers was unknown in most cases, it is impossible to calculate a response rate for the study.

To be eligible to participate, individuals had to meet two criteria: (1) Currently residing with a spouse with chronic, irreversible dementia, and (2) acting as primary

caregiver for the demented spouse. Patients were considered to have dementia if they met either one of the following criteria: (a) a score of 26 or below on the Mini Mental State Exam (Folstein, Folstein, & McHugh, 1975; Monsch, Foldi, Ermini-Funfschilling, Berres, Staehelin, & Spiegel, 1993) and dementia symptoms of at least two months' duration (to rule out patients suffering from an acute condition involving dementia symptoms such as dehydration or adverse reaction to medication), or (b) a diagnosis of dementia confirmed by a physician or psychologist.

Dementia symptoms were chosen as the criterion for inclusion, rather than a specific diagnosis, as there is a great deal of ambiguity involved in making a differential diagnosis of Alzheimer's disease. Moreover, the study hypotheses describe the impact of the symptoms of dementia on the caregiver, rather than the cause of those symptoms.

All participants were assured that participation in the study was voluntary, and that their answers would be kept strictly confidential. Participants' names did not appear on the questionnaires, making it impossible to identify individual respondents from their responses. This information was repeated in a written consent form signed by spouses prior to beginning the structured interview (see Appendix A). Spouses also gave consent for patients to complete the Mini Mental State Exam. When the patient was able to understand the research, he or she was asked to sign

a separate consent form.

Sample characteristics

The sample of caregiving spouses was predominantly female (68.5%), white (94.4%; 3.7% black; 1.9% Hispanic), and of moderate income (see Table 1 for sample characteristics). The majority of the sample (87%) had completed high school, and approximately one quarter were college graduates. One fifth of the sample was employed either full or part time. Most couples had been married for many years (M=42.79 years; range=9-63 years), and most (88.9%) had had children together. The majority of caregivers reported their own health to be good (47.2%) or excellent (34.0%) compared to other people their age.

Almost two thirds of the patients (60%) had been diagnosed with dementia within the past three years. The most common diagnosis was probable Alzheimer's disease (61.2% of patients); other diagnoses included Multi-Infarct Dementia (11.1%), Alzheimer's and Multi-Infarct (3.7%), and Hydrocephalus (3.7%). One fifth of the sample had not been given a definitive diagnosis of the illness that was causing the dementia.

Table 1

Sample Characteristics

Characteristics of Spouse Caregivers

Variable	Categories	%	(n)
Sex	Female	68.5%	(37)
	Male	31.5%	(17)
Ethnicity	White	94.4%	(51)
	Black	3.7%	(2)
	Hispanic	1.9%	(1)
Education	9-11 years	12.0%	(7)
	High School graduate	35.2%	(19)
	Some college	16.7%	(9)
	College graduate	14.8%	(8)
	Grad/profession school	20.4%	(11)
Occupational Status	Full time	13.0%	(7)
	Part time	9.3%	(5)
	Retired	57.4%	(31)
	Homemaker	18.5%	(10)
	Unemployed	1.9%	(1)
Annual Income	Under $10,000	8.3%	(4)
	$10,000-20,000	27.1%	(13)
	$21,000-30,000	22.9%	(11)
	$31,000-50,000	16.7%	(8)
	$51,000-70,000	14.6%	(7)
	Over $70,000	10.4%	(5)

Table 1 (continued)

Variable	Categories	% (n)
Health	Excellent	34.0% (18)
	Good	47.2% (25)
	Fair	17.0% (9)
	Poor	1.9% (1)
Children	Yes	88.9% (48)
together	No	11.1% (6)
Paid Help	Yes	50.0% (27)
	No	50.0% (27)
Age	M=70.47 years (SD=8.67)	Range=52-88
Years Married	M=42.79 years (SD=12.08)	Range= 9-63
Informal helpers	M= .70 people (SD=1.09)	Range= 0- 4
Availability of support	M= 4.30 people (SD=2.86)	Range= 0- 9

Characteristics of Dementia Patients

Variable	Categories	% (n)
Diagnosis	Alzheimer's	61.2% (33)
	Multi-infarct dementia	11.1% (6)
	Alzheimer/Multi-infarct	3.7% (2)
	Hydrocephalus[a]	3.7% (2)
	Dementia	20.4% (11)

Table 1 (continued)

Variable	Categories	% (n)
Time Since First Symptoms	<1 year	1.9% (1)
	1-3 years	30.2% (16)
	3-5 years	32.1% (17)
	5-7 years	13.2% (7)
	7-10 years	7.5% (4)
	>10 years	15.1% (8)
Time Since Diagnosis	<1 year	16.0% (8)
	1-3 years	44.0% (22)
	3-5 years	26.0% (13)
	5-7 years	6.0% (3)
	7-10 years	6.0% (3)
	>10 years	1.9% (1)
Age	M=74.17 years (SD= 7.82)	Range=56-85

[a] One patient whose spouse reported a diagnosis of hydrocephalus also had a diagnosis of multi-infarct dementia confirmed by neurologists' report.

Measures

A copy of the interview protocol, including all study measures, is presented in Appendix B. Descriptive statistics and internal consistency reliabilities for all scales used in analyses can be found in Table 2, and intercorrelations in Table 3. With the exception of the Mini Mental State Exam administered to dementia patients, all data were collected from caregiving spouses.

Table 2

Descriptive Statistics and Reliabilities

Variable	Mean	SD	Range	Alpha
ADL/IADL	4.50	4.01	0- 13	.91
Hours of care (per day)	8.55	6.17	1- 19	--
Memory and Behavior Problems (MBPC)	73.02	26.05	10-131	.85
Mini Mental State (MMSE)	12.22	9.15	0- 29	.91
Adaptability	26.90	6.49	12- 42	.68
Caregiver burden	31.85	13.58	2- 62	.83
Depression (CES-D)	13.69	8.49	0- 39	.79

Table 3

Intercorrelations among study variables

	1	2	3	4	5	6	7
1. ADL/IADL	---						
2. Hours of care	-.20						
3. MBPC	-.41**	.56***					
4. MMSE	.68***	-.12	-.38**				
5. Adaptability	-.00	-.07	-.12	-.22			
6. Role Choice[a]	-.48***	.14	.23t	-.41**	.13		
7. Burden	-.19	.22	.44***	-.10	-.02	.17	
8. CES-D	-.29*	.24t	.36**	-.07	-.08	.08	.67***

t $p < .10$; * $p < .05$; ** $p < .01$; *** $p < .001$

Note: ADL/IADL=Activities of Daily Living/Instrumental Activities of Daily Living; MBPC=Memory and Behavior Problems Checklist; MMSE=Mini Mental State Exam; CES-D= Center for Epidemiologic Study Depression Scale.

[a] 1=Spouse, 2=Caregiver

Caregiver stress measures

Patients' mental impairment. The Mini Mental State Exam (MMSE; Folstein et al., 1975) served as a screening tool to determine the severity of patients' dementia symptoms. The MMSE is a brief and easily administered test of cognitive functioning. It can differentiate patients at different levels of cognitive functioning and is not biased by the presence of other psychological disorders such as depression. Scores range from 0-30, with lower scores indicating more severe mental impairment.

Couples were included in the study if the patient scored 26 or below. A recent study (Monsch et al., 1993) suggests that earlier research using the MMSE did not adequately sample patients with mild dementia; they suggest that a cutoff score of 26 provides for maximal sensitivity to detect dementia and enough specificity to prevent including patients who do not actually suffer from dementia. They caution, however, that some patients in the earliest stages of a dementing illness, or patients with higher levels of education, may score above 26 and still suffer from mild dementia. Thus, patients scoring above 26 were included if a confirmed diagnosis of dementia was obtained from the patient's physician or psychologist.

Behavior problems. To assess the level of memory impairment and behavioral problems that caregivers face, spouses completed the Memory and Behavior Problems Checklist

(MBPC; Zarit & Zarit, 1982, 1987). Caregivers rated the frequency of 32 disturbing, socially inappropriate or aggressive behaviors on a five-point scale (0=never occurred; 5=occurs daily or more often). Higher scores indicate greater memory and behavior disturbance. Exemplary items are "asking the same question over and over;" "trouble remembering significant events from the past;" "not recognizing familiar people;" "wandering or getting lost;" and "engaging in behavior that is potentially dangerous to self or others."

Physical impairment. Caregivers completed measures of patients' need for assistance with six basic Activities of Daily Living (ADL: bathing, dressing, eating, grooming, ambulation, and toileting), and Instrumental Activities of Daily Living (IADL: using a telephone, shopping, food preparation, housekeeping, laundry, travelling, taking medication, and handling finances; Lawton & Brody, 1969). ADL/IADL impairment is a widely used indicator of functional disability among older adults, allowing comparison across studies.

Each item is coded as a dichotomous variable (1=completely independent or 0=needs help) and summed. ADL and IADL impairments were combined into a single scale of patient functioning with a range of 0 (needs help in all areas) to 14 (totally independent in all areas).

Although one would expect patients' level of mental and

physical impairment to be related, there is research evidence that the two types of impairment represent separate dimensions (e.g., Moritz et al., 1989). In this study, ADL/IADL independence was moderately correlated with memory and behavior problems (r= -.41, p <.01).

Time spent caregiving. Caregiving spouses were asked approximately how many hours per day they spend caring for or supervising the patient. Time spent caregiving ranged from less than 2 hours to more than 18 hours per day.

Family coping and role measures

Adaptability was measured using the adaptability subscale of the Family Adaptability and Cohesion Scale, couples version (FACES III; Olson et al., 1985; Olson, 1986). FACES III is the most widely used self-report measure of family adaptability, permitting comparison of these findings with other research. The 10-item adaptability subscale assesses the frequency with which couples make changes in leadership roles, the division of household labor, methods of problem solving and expectations of one another, and share decision making. Exemplary items include "When problems arose, we compromised;" "We were flexible in how we handled our differences;" "Different persons acted as leaders in our marriage;" and "It was hard to tell who did which household chores." Each item is scored on a 5 point scale (1=almost never; 5=almost always). Items were summed to yield a scale score with a possible

range of 10 to 50, with higher scores indicating greater adaptability.

Spouses completed the scale retrospectively, considering their marriage prior to illness onset. The items ask spouses to describe actual patterns of behavior within the marriage (e.g., "We shifted household responsibilities from person to person"), rather than feelings about or satisfaction with their marriage. Such descriptions of longstanding behavior patterns should be more accurate when reported retrospectively than might be the case for more affective or evaluative measures.

Previous research utilizing the scale has reported good convergent and discriminant validity. Adaptability is not correlated with the family cohesion subscale of FACES III, nor with social desirability, indicating that the adaptability scale is measuring an aspect of family functioning distinct from family closeness and interconnectedness, and is not contaminated by socially desirable responding (Olson et al., 1985). Another study used factor analysis to test both convergent and discriminant validity with a sample of 121 married couples (Edman, Cole, & Howard, 1990). Scores for the FACES III adaptability subscale loaded on the same factor as scores for a similar construct, the organization and control subscales of the Family Environment Scale, providing evidence of convergent validity. Measures of cohesion and

talkativeness each loaded on distinct factors, providing further evidence of divergent validity.

Family role was assessed using a modification of Bowers' (1990) forced-choice methodology. Spouses were asked "If you had to choose a phrase to describe your role right now, which of the following would come closest?" Spouses were given a choice of two roles: "I am the wife or husband of a person with dementia" or "I am the caregiver for a person with dementia." Only two individuals were unable to choose either the spouse or caregiver role. Twenty eight individuals (53.8%) endorsed the spouse role and 24 individuals (44.4%) chose the caregiver role.

Outcome variables

Caregiver burden was measured using the Burden Interview (Zarit et al., 1980; Zarit & Zarit, 1987). The 22-item scale assesses caregivers' reactions to a range of stressors related to caregiving, such as decreased personal time, diminished social life, embarrassing behavior, or arguments with patients. The Burden Inventory is probably the most widely used measure of caregiver burden (Dillehay & Sandys, 1990), allowing easy comparison of the data with other studies.

Psychological distress. The Burden Interview assesses the distress caregivers experience specific to caregiving. In order to assess the impact of caregiving stress on spouses' general well-being, a measure of depression was

included. The Center for Epidemiologic Study Depression Scale (CES-D; Radloff, 1977), is a 20-item scale designed to measure depressive symptoms in the general population. The CES-D has been used successfully with older adults in general, and with spouse caregivers in particular (Lawton et al., 1991). Caregivers were asked to indicate on a 4-point scale (0=rarely; 3=most of the time) how often they had experienced each symptom of depression during the past week. The scale has a possible range of 0-60, with higher scores indicating greater depressive symptomology. A score of 16 or above indicates that an individual may be at risk for clinical depression (Radloff, 1977).

Demographic and dementia-related variables

The following demographic variables were assessed: age, gender, ethnicity, length of marriage, income, educational level, employment status, health of the caregiver compared to others of the same age. The following characteristics of the patient's dementia were assessed with single-item variables: diagnosis, length of time since symptoms were first noticed, length of time since diagnosis, availability of informal help with caregiving (from family or friends), frequency of informal help from each helper, availability and frequency of paid help.

Statistical power of the study

With a sample size of 54, statistical power to detect moderate effect sizes at $p < .05$ in a regression equation

with four independent variables is limited, at only .55 (Cohen, 1988). In light of this, findings will be discussed if they are significant at $p<.10$ or less. When a finding at significance levels between $p<.05$ and $p<.10$ is reported, the significance level will be noted in the text, and caution will be taken not to over interpret any single significant result.

Results

Magnitude of the stressor

Most caregivers were caring for partners with moderate to severe impairment in many areas, although all levels of impairment were represented in the sample. Scores on the Mini Mental State Exam (Folstein et al., 1975) ranged from 0 to 29, with a mean of 12.2, suggesting pronounced cognitive impairment. Spouses were also coping with frequent memory and behavior problems, and functional impairment was extensive. The mean score of 4.5 on the combined ADL/IADL index indicates independence in only 4 or 5 activities. Scores ranged from 0 (unable to perform any activity unassisted) to 13 (independent on all but one activity). Reflecting these impairments, caregivers devoted an average of 8.6 hours per day caring for their partners, with 11.3% spending more than 18 hours per day providing care and supervision.

The degree of caregiver burden in this sample was moderate and comparable to scores found in other studies of

spouse caregivers (e.g., Zarit et al., 1980; Zarit et al., 1986). Spouse caregivers in this sample were experiencing elevated levels of depressive symptoms as compared to other community residing samples (Radloff, 1977), and one other study of spouse caregivers to dementia patients (Moritz et al., 1989). However, other research with dementia caregivers found elevated levels of depression similar to those found in this sample (Biegel et al., 1991).

Potential covariates

Caregiving spouses' level of education was significantly related to depression (r =-.31, p <.02), such that spouses with higher levels of education experienced fewer depressive symptoms. Spouses' education was unrelated to level of caregiver burden. Therefore, spouses' education was included as a covariate in analyses when caregiver depression was the criterion variable.

No other demographic variables (age, sex, income, caregiver health) or dementia-related variables (duration of symptoms, time since diagnosis, availability of informal or paid help with caregiving) were related to spouses' level of caregiver burden or depression. Caregivers who used paid help did not differ from those without paid help in duration of symptoms, time since diagnosis, level of adaptability, patient's level of mental or functional impairment, frequency of memory and behavior problems, gender, burden or depression.

Correlates of adaptability

Adaptability was not significantly related to any demographic or dementia-related characteristics, including spouses' age, sex, income, education, caregiver health, duration of symptoms, time since diagnosis, availability of informal or paid help with caregiving. Adaptability was also unrelated to patients' level of functional impairment, memory and behavior problems, cognitive impairment, or the hours of care provided by caregiving spouses.

Hypothesis 1: Adaptability and role choice

The first study hypothesis predicted that caregiving spouses with more adaptable styles would be more likely to maintain a spouse role in relation to the patient, whereas less adaptable caregiving spouses would be more likely to adopt a caregiver role. This hypothesis was not confirmed (see Table 4). The individuals who endorsed a caregiver role did not differ from those who endorsed a spouse role in adaptability. Controlling for patients' level of physical impairment, cognitive impairment, and memory and behavior problems did not alter this finding ($F = 1.45$, ns).

Instead, the severity of the patient's condition was associated with role choice (Table 4). Caregiving spouses who endorsed the caregiver role were caring for partners who were more functionally and cognitively impaired. Their partners also exhibited more memory and behavior problems ($p<.10$). The amount of time spent caring for the patient

did not differentiate participants who endorsed the spouse vs. caregiver role.

Table 4

Comparison of participants endorsing a spouse vs. caregiver role

	Role Choice		
Variable	Spouse (n=28) (M)	Caregiver (n=24) (M)	t value
ADL/IADL	6.40	2.54	3.87***
Hours of care	7.67	9.42	-1.02
MBPC	67.28	79.51	-1.69^{t}
MMSE	15.93	8.50	3.14**
Adaptability	25.93	27.57	- .91
Burden	30.11	34.71	-1.21
CES-D	13.39	14.75	- .57

^{t} $p < .10$; ** $p < .01$; *** $p < .001$

Note: ADL/IADL=Activities of Daily Living/Instrumental Activities of Daily Living; MBPC=Memory and Behavior Problems Checklist; MMSE=Mini Mental State Exam; CES-D= Center for Epidemiologic Study Depression Scale

Hypothesis 2: Adaptability as a moderator of the predictors of burden and depression

The second study hypothesis predicted that neither

caregiving spouses' level of adaptability nor the role they adopted in relation to the patient would be directly related to caregiver burden or depression. Instead, it was hypothesized that adaptability would serve as a moderator of the relationship between caregiving stress and caregivers' level of burden and depression. Specifically, it was predicted that the stress of the practical demands of caregiving would be more strongly related to spouses' burden and depression when adaptability was low, whereas the stress of patients' mental impairment would be more strongly related to burden at higher levels of adaptability.

As shown in Table 3, adaptability was not correlated with caregiver burden or depression. Similarly, caregiving spouses who endorsed a spouse role did not differ from those who endorsed a caregiver role on either burden or depression (Table 4).

Hierarchical multiple regression analysis was utilized to test the moderation hypotheses. Hours of care was included in the regression equations as the measure of caregiving stress reflecting the concrete demands of caregiving. Hours of care was chosen rather than ADL/IADL impairment because half of the caregiving spouses in the sample utilized paid assistance in caring for their partners. Thus, the amount of time each day that caregivers themselves spent in caring for their impaired partners served as the more accurate measure of the practical demands

of caregiving on spouses. The Memory and Behavior Problems Checklist (MBPC) served as the measure of caregiving stress reflecting patients' mental impairment, as the scale reflects the day to day problems that caregivers face specifically related to patients' mental and behavioral deterioration.

Centered scores were created for hours of care, memory and behavior problems, and adaptability, by subtracting the sample mean score from the individual subject's raw score. This procedure reduces problems of multicollinearity among predictor variables when computing interaction terms (Finney, Mitchell, Cronkite, & Moos, 1984).

Separate regression equations were constructed for the two criterion measures of caregiver burden and depression. Spouse's level of education was entered into the equation as a covariate when the criterion variable was caregiver depression. The caregiving stress variables (hours of care and MBPC) were entered as a set on the next step to assess their direct effects. Adaptability, the moderator variable, was entered on the next step, followed by product interaction terms for adaptability and hours of care, and adaptability and memory and behavior problems. These two product terms were entered as a set on the last step of the regression equation to test for interaction effects.

The results of the regression equation with caregiver burden as the criterion measure are presented in Table 5.

Only the set of caregiving stress variables explained a significant proportion of the variance in caregiver burden. The regression weights indicated that memory and behavior problems were more strongly associated with caregiver burden than hours of care. This finding is consistent with the zero order correlations, in which memory and behavior problems were highly correlated with caregiver burden (r=.44, p<.001), while hours of care were not (r=.22, ns). Although the zero-order correlation between education and burden was non-significant, this regression analysis was repeated with spouse's education entered as a covariate to mirror the regression equation with depression; the results of the regression were unaffected.

The results were somewhat different when caregivers' level of depression was considered as the criterion measure, as shown in Table 6. Again, the set of caregiving stress variables explained a significant proportion of the variance, with memory and behavior problems the stronger predictor. However, the set of interaction terms also explained a significant proportion of the variance in depression, at the p<.10 level of significance.

Table 5

Regression of caregiver burden on stress, adaptability, and their interactions

Predictor	/\R^2	F/\	Beta	R^2	Adj R^2	F
Caregiving Stress	.19	6.02**				
MBPC			.44			
Hours of care			-.03			
Adaptability	.00	.08	.04			
Interaction Terms	.02	.66				
MBPC X Adaptability			-.03			
Hrs X Adaptability			-.19			
Full equation				.22	.13	2.61*

t p<.10; * p<.05; ** p<.01; *** p<.001

Note: MBPC=Memory and Behavior Problems Checklist

Table 6

Regression of depression on stress, adaptability, and their interactions

Predictor	/\R²	F/\	Beta	R²	Adj R²	F
Education[a]	.10	5.45*	-.31			
Caregiving Stress	.12	3.80*				
MBPC			.35			
Hours of care			.03			
Adaptability	.00	.00	.01			
Interaction terms	.09	3.06[t]				
MBPC X Adaptability			-.03			
Hrs X Adaptability			-.31			
Full equation				.31	.22	3.44**

[a] Spouses' education was entered as a covariate.

[t] p<.10; * p<.05; ** p<.01; *** p<.001

To clarify the nature of these interaction effects, separate regression equations were computed for each of the stressor variables (hours of care and MBPC), with caregiver depression as the criterion measure. Education was entered first as a covariate. The caregiving stressor (either hours of care or memory and behavior problems) was entered on the second step, the moderator variable (adaptability) was entered next, and the interaction term of the stressor and moderator was entered on the final step.

As in the combined equation, memory and behavior problems alone explained significant variance in caregiver depression, with more memory problems related to greater depression (Table 7). The interaction of memory and behavior problems and adaptability also explained a unique proportion of the variance, at the $p<.10$ level of significance. When hours of care was considered as the stressor variable, there was no main effect, but the interaction term of hours of care and adaptability was significant. In neither equation did adaptability explain a significant amount of variance.

Table 7

Regression of depression on measures of stress, adaptability, their interaction

Predictor	/\R^2	F/\	Beta	R^2	Adj R^2	F
Stress measure: Memory and Behavior Problems						
Education[a]	.10	5.56*	-.31			
MBPC	.12	7.85**	.35			
Adaptability	.00	.01	.01			
MBPC X Adaptability	.04	2.83t	-.21			
Total equation				.26	.20	4.30**
Stress measure: Hours of Care						
Education[a]	.10	5.45*	-.31			
Hours of care	.05	2.73	.22			
Adaptability	.00	.02	-.02			
Hrs X Adaptability	.08	5.22*	-.30			
Full equation				.23	.16	3.53**

[a] Spouses' education was entered as a covariate.

t $p<.10$; * $p<.05$; ** $p<.01$; *** $p<.001$

Regression lines were plotted to clarify the nature of the interaction effects. As shown in Figure 2, at low levels of adaptability, providing more hours of care to a partner with dementia was related to greater caregiver depression. In fact, levels of depression among caregivers with low adaptability who were providing many hours of care were the highest for the sample ($\underline{M}$=17.6) and slightly above the CES-D cutoff score of 16 indicating elevated risk for clinical depression (Radloff, 1977). For caregivers high in adaptability, there was no relationship between hours of care and caregiver depression.

The interaction of memory and behavior problems and adaptability was similar, but less pronounced (see Figure 3). Among all caregivers, greater memory and behavior problems were related to higher depression levels, but this relationship was strongest for caregiving spouses scoring lower on adaptability and weakest among those high in adaptability.

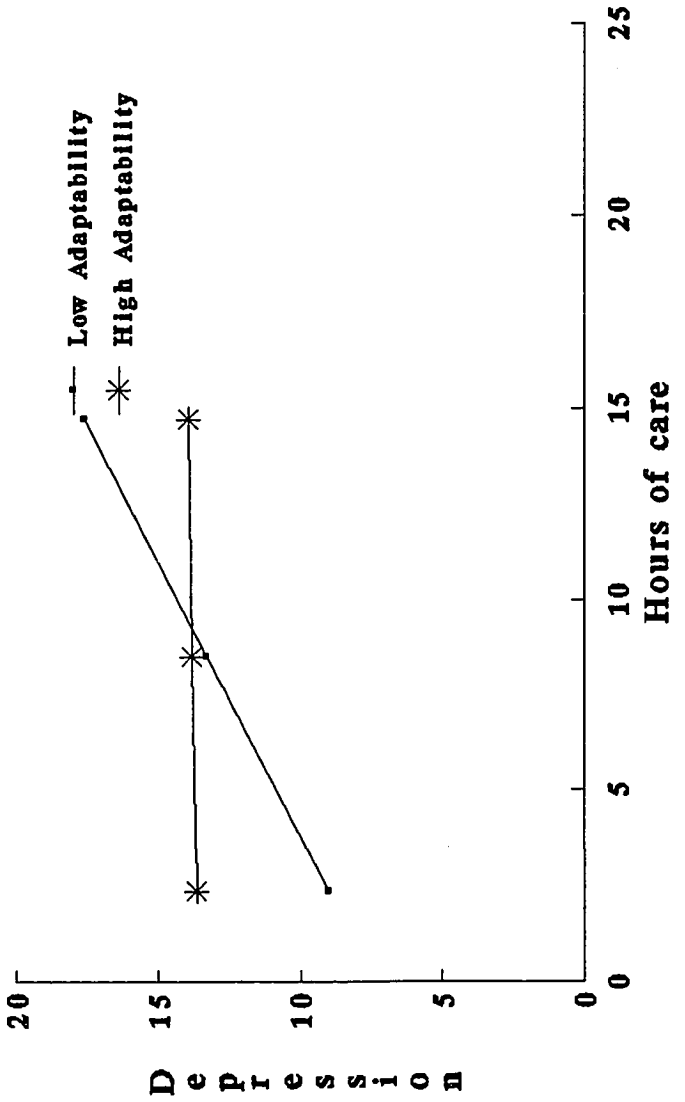
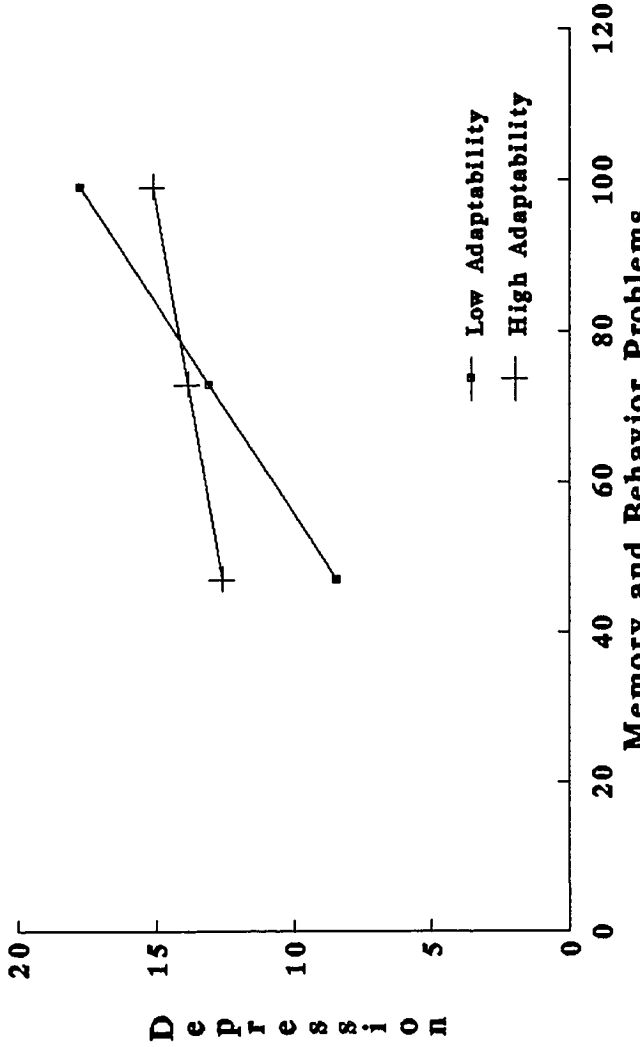


Figure 2
Interaction of hours of care with adaptability

Figure 3
Interaction of memory and behavior problems with adaptability



Taken together, these regression analyses partially confirm the second study hypothesis. Adaptability moderated the impact of caregiving stress on spouses' level of depression, but not on burden. The interaction of the concrete demands of caregiving (hours of care) and adaptability was in the expected direction, such that hours of care was more strongly related to depression when adaptability was low. However, the nature of the interaction effect of memory and behavior problems and adaptability was not as expected. Contrary to prediction, memory and behavior problems were more strongly related to depression when adaptability was low.

An alternative test of Hypothesis 2

The regression analyses describe the degree to which adaptability and caregiving stress explain individual variation in caregivers' depression and burden. It is also important to understand whether certain configurations of stress and coping styles are related to lower psychological distress.

To examine this, cluster analysis was used to develop profiles of caregivers based on their patterns of caregiving stress, adaptability, and role choice (spouse or caregiver). Ward's method with a squared Euclidean distance resemblance coefficient was chosen to form clusters with minimal variance within clusters and maximal differences between clusters (Aldenderfer & Blashfield, 1984; Revenson & Cassel,

1991). Five variables were included in the cluster analysis: patients' functional independence (ADL/IADL), hours of care, patients' memory and behavior problems, adaptability, and role choice (spouse or caregiver). Standardized (Z) scores were computed for all variables to permit profile analysis.

The three-cluster solution yielded clusters of adequate size with meaningful differences between clusters in the configuration of stressors, role choice, and adaptability (see Figure 4). All five variables were significantly different across the clusters, indicating that they all contribute significantly to the cluster solution (see Table 8).

Two of the clusters (1 and 3) represent virtually opposite configurations of patient impairment, hours of care, adaptability, and role choice. Members of Cluster 1, named Adaptable Caregivers, were caring for partners with low levels of physical functioning and high levels of memory and behavior problems relative to the sample means. They provided many hours of care (an average of 9.42 hours per day) and all but one of these 24 individuals considered themselves to be caregivers to their demented partners rather than spouses. Levels of adaptability were close to the sample mean.

Table 8

Analysis of variance by cluster membership

	Cluster Means[a]			
	1	2	3	
Variable	(n=24)	(n=10)	(n=17)	F (2,48)
ADL/IADL	-.49 (2.54)	-.60 (2.10)	1.11 (8.95)	33.83***
Hours of care	.14 (9.42)	.40 (11.00)	-.46 (5.71)	3.11*
MBPC	.25 (79.43)	.70 (91.20)	-.68 (55.35)	9.29***
Adaptability	.23 (28.37)	-1.12 (19.60)	.26 (28.59)	10.11***
Role Choice [b]	.99	-.72	-.92	140.09***
	(23 caregivers	(1 caregiver	(0 caregivers	
	1 spouse)	9 spouses)	17 spouses)	

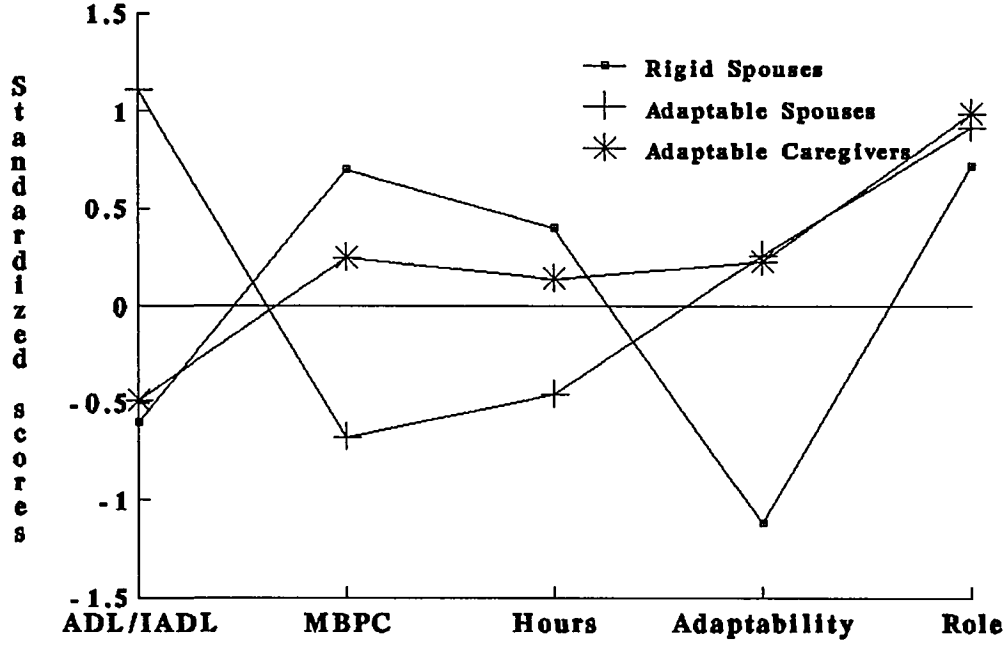
* $p < .05$; *** $p < .001$

[a] Means are reported as standardized score (actual score).

[b] Role choice was coded as 1=spouse; 2=caregiver.

Note: ADL/IADL=Activities of Daily Living/Instrumental Activities of Daily Living; MBPC=Memory and Behavior Problems Checklist

Figure 4
Cluster profiles of caregiving spouses



Note: ADL/IADL=Activities of daily living/Instrumental activities of daily living; MBPC=Memory and behavior problems checklist; Hours=Hours of care per day; Role=Role choice (1=spouse, 2=caregiver)

In contrast, the Adaptable Spouses in Cluster 3 were caring for a spouse with relatively high levels of functional independence and low levels of memory and behavior problems. They spent relatively few hours per day providing care to their partners compared to the sample as a whole (M=5.71 hours vs. 8.55 hours), and all considered themselves to be spouses. Again, levels of adaptability were near the mean for the sample as a whole.

A more unusual profile emerged in Cluster 2, labeled Rigid Spouses. These spouses were caring for patients with low levels of physical functioning, and memory and behavior problems even more pronounced than those found in Cluster 1. They spent the most time caring for their partner of any caregivers in the sample (an average of 11 hours per day). Yet, all but one member of this group considered themselves to be spouses rather than caregivers. Levels of adaptability were well below the sample mean.

Analyses of variance and chi-square analyses compared the three clusters of caregiving spouses on demographic characteristics and on levels of caregiver burden and depression. There were no significant differences among the three clusters in age, sex, education, or time since diagnosis. Time since first dementia symptoms was significantly greater for Adaptable Caregivers than for Adaptable Spouses, reflecting the higher levels of patient impairment that characterize this cluster. However, Rigid

Spouses did not differ significantly from the other two clusters on length of time since first dementia symptoms.

Echoing the findings of the regression analyses presented earlier, there were no differences among the clusters in level of caregiver burden (see Table 9). There were significant differences in level of depression: Rigid Spouses experienced significantly higher levels of depression than the two clusters of more adaptable caregiving spouses. The mean level of depression for Rigid Spouses (M=19.60) falls above the cutoff for clinical levels of depression.

Table 9

Analysis of variance in depression and burden by cluster membership

	Cluster Means			
	1	2	3	
Variable	(n=24)	(n=10)	(n=17)	F (2,48)
Burden	33.87	37.50	27.71	1.91
Depression	14.33	19.60	10.24	3.72*

* p<.05

Discussion

While memory and behavior problems were associated with greater depression for all caregiving spouses, providing

long hours of care was associated with greater depression only among spouses low in family adaptability. Similarly, the choice of a spouse or caregiver role was not associated with caregivers' depression when considered alone. However, the combination of low adaptability, severe patient impairment, and choice of a spouse role was associated with higher caregiver depression. These findings highlight the multidimensional nature of caregiving, and the importance of family adaptability as a moderator of caregiver stress.

The majority of caregiving studies are grounded in the traditional stress and coping paradigm, focussing primarily on the individual caregiver's response to stress. By examining the relationships among family adaptability, marital roles, and spouses' psychological adjustment to caregiving, this study moves beyond the existing research by considering the context in which caregiving takes place -- the ongoing relationship between patient and spouse.

Adaptability as a moderator of caregiving stress

As hypothesized, family adaptability was not directly related to caregiver burden or depression. Instead, it served as a moderator of the relationship between caregiving stress and spouses' depression. Contrary to expectations, spouses' level of adaptability was not related to differences in the aspect of caregiving they found most troubling. Instead, both the amount of time spent in caregiving tasks and patients' mental deterioration were

associated with greater depression among less adaptable caregiving spouses.

Adaptability seems to act as a coping resource that buffers the negative impact of caregiving demands. A resource can be said to act as a stress buffer if its impact on well-being is most evident under conditions of stress, showing a greater impact as the level of stress increases (Cohen & Wills, 1985). Perhaps more adaptable caregivers were able to develop new strategies for coping with the demands of caregiving, or were more willing to accept changes in their partners' behavior and abilities. At lower levels of stress, fewer changes are required in the way caregivers interact with the patient, limiting the importance of adaptability for caregiver well-being.

Considering these findings within the framework of Lazarus and Folkman's (1984) stress and coping theory, the degree to which caregiving spouses can adapt to change may affect their appraisal of a situation as stressful. Greater flexibility may decrease the threat that spouses feel when they face changes in their relationship with the patient, or allow them to feel that their personal resources are adequate to meet the demands of the situation.

The buffering effect of adaptability on caregiver depression was stronger for hours spent caregiving than for memory and behavior problems. Adaptability may be especially important when caregivers face the constant work

and vigilance that long hours of caregiving entail. Less adaptable caregivers may find it difficult to adjust their daily routines to accommodate extensive caregiving demands. In fact, long hours of care seem to have little negative impact on psychological well-being for more adaptable caregivers.

In contrast, the interaction effect of memory and behavior problems with adaptability was much weaker. Unlike hours of care, which represent concrete demands on the caregiver, memory and behavior problems are one of the primary manifestations of cognitive decline. These data suggest that caregivers have a great deal of difficulty in coming to terms with patients' mental deterioration regardless of the level of adaptability they can bring to bear on coping with other aspects of the illness.

The weak interaction effect that did emerge may be a function of shared variance between memory and behavior problems and hours of care. It is possible that the additional hours of care required by patients with more severe memory and behavior problems accounted for the interaction effect of memory and behavior problems with adaptability when this interaction was entered into the regression equation alone. When the two interaction terms (memory and behavior problems with adaptability and hours of care with adaptability) were entered into the regression equation as a set, the interaction of memory and behavior

problems with adaptability was no longer significant. Alternatively, the strong association between memory and behavior problems and depression may account for the weaker interaction effect; even the most adaptable caregivers experience greater depression when memory and behavior problems are more severe. It also cannot be ruled out that the interaction of memory and behavior problems with adaptability occurred by chance, as the significance level of this interaction term was at the .10 level.

Although the negative impact of caregiving stress was evident for both caregiver burden and depression, adaptability served as a moderator of that stress only for depression. This was surprising in light of the strong correlation between caregiver burden and depression in this study (r=.67). However, other researchers have also reported different correlates of burden and depression (Poulshock & Deimling, 1984; Williamson & Schulz, 1990). Caregiver burden encompasses distress specific to caregiving and the negative impact of specific problems on caregivers' lives. Therefore, it makes sense that feelings of burden are closely tied to the actual day-to-day problems that caregivers face. In contrast, depression involves more global manifestations of sadness and hopelessness. Although burden is an understandable result of the overwhelmingly difficult task of caring for a loved one with dementia, depression may represent a maladaptive response to the

stresses of caregiving. An inflexible style of facing problems may be ill-suited to the extreme challenges of caring for a spouse with dementia, and may predispose caregivers to greater psychological distress under conditions of extreme stress. It should be noted that the data do not indicate that flexible spouses were doing exceptionally well in the face of caregiving stress; instead, it was the least flexible spouses who were doing poorly when hours of care were long.

Adaptability and role choice

Considered alone, the role that caregiving spouses endorsed was not directly associated with level of adaptability in correlational and regression analyses. However, differences in spouses' depression did emerge when role choice, adaptability and patients' level of impairment were considered together. The results of the cluster analysis suggest that the combination of endorsing a spouse role, low adaptability, and severe patient impairment across all areas of functioning was related to greater caregiver depression.

This combination of factors suggests that adaptability may affect the point at which caregiving spouses are able to accept a change in the role they play in their partners' lives. Most spouses in the sample endorsed a role that was responsive to their partners' level of mental and functional impairment. When patients were dependent in the majority of

activities of daily living and exhibited marked memory and behavior problems, respondents tended to consider themselves as caregivers rather than spouses (Adaptable Caregivers), reflecting the reality of the patients' limitations. Similarly, when patients were less severely impaired, most respondents endorsed a spouse role (Adaptable Spouses). In open-ended responses, caregivers clearly described the distinction between spouse and caregiver roles. As one woman put it, "He's completely dependent. I've lost a husband. He's like a child." Or, as another woman described her situation, "If you lose the man, you've lost everything. You don't have a marriage anymore."

In contrast to caregivers who had come to terms with the loss of a spousal role, a small group of caregiving spouses, who scored well below the sample mean on adaptability, endorsed a spouse role <u>despite</u> their partners' extreme mental and functional impairment. These Rigid Spouses experienced higher levels of depressive symptoms than other caregivers in the sample. Perhaps these individuals were unable to alter their conception of their relationship, despite strong evidence that the patient was no longer able to act as a true partner. The failure of these relationships to meet outdated expectations may have resulted in the elevated depression levels experienced by members of this cluster.

In a recent study of spouse and adult child caregivers

(Aneshensel, Pearlin, & Schuler, 1993), feelings of role captivity -- "being an unwilling, involuntary incumbent of the caregiver role" -- were associated with deciding to institutionalize the patient. The notion of role captivity may shed light on the cluster analysis findings. Greater adaptability may have allowed spouses caring for more impaired patients to acknowledge their caregiver role and to maintain positive psychological well-being despite the constraints of that role. Thus, more adaptable spouses caring for severely impaired partners endorsed the caregiver role, and experienced lower levels of depression. In contrast, less adaptable spouses caring for similarly impaired partners did not acknowledge their status as caregivers. They continued to endorse a spouse role and experienced elevated levels of depression.

Unfortunately, causal relationships between adaptability, role choice, and depression could not be tested. As the data were cross-sectional, it was impossible to determine whether the combination of an unrealistic role choice and low adaptability is related to higher depression when patients are more impaired across all areas of functioning, or whether low adaptability actually prevents caregiving spouses from adopting a more realistic role in relation to their partners with dementia.

What does the concept of adaptability add to the caregiving literature?

This study, as it was originally conceived, hypothesized a strong role for adaptability as a moderator of caregiver burden and depression. The results suggest a much more limited role of adaptability in explaining levels of caregiver burden and depression. Methodological issues, such as the small sample size or error in the measurement of adaptability, may account for some of the absence of findings. However, the pattern of findings suggests that rethinking the original hypotheses is in order.

Providing care to a spouse with dementia is an overwhelmingly stressful situation that affects every aspect of the caregiver's life. For caregivers in this study, the realities of the caregiving situation, such as the severity of patients' physical and mental impairment, proved to be the best explanatory factor in their choice of a spouse or caregiver role. Frequent memory and behavior problems were related to greater burden and depression for all caregivers, regardless of their level of adaptability. It may have been naive to propose such a prominent role for adaptability in the face of such pervasive, chronic, and uncontrollable stressors.

Yet, it is also too early to dismiss adaptability altogether. In both the regression and cluster analyses, adaptability emerged as a moderator of the relationship

between caregiving stress and caregivers' depression. Although a relatively small proportion of the variance in depression was explained by this moderating effect of adaptability, the data point to particular caregiving situations in which low adaptability may be problematic for spouse caregivers. When the time constraints of caregiving were high, or when the combined demands of time constraints, behavioral problems and functional impairment were all severe, and caregiving spouses endorsed a role that did not reflect the realities of patients' impairment, caregivers experienced elevated levels of depression. These findings suggest that a combination of person and environment factors may contribute to spouses' psychological adjustment to caregiving.

In light of the research findings, the theoretical model originally proposed should be revised. Initially, it was hypothesized that spouses' level of adaptability would be related to the role they adopted in relation to the patient, and that this difference in marital roles would in turn be related to different predictors of burden and depression. However, the data indicate that adaptability was not directly related to role choice. Nonetheless, adaptability did serve as a moderator of the relationship between caregiving stress and depression. If this moderating effect was not related to role choice, as originally hypothesized, how does adaptability work?

The items of the adaptability scale ask spouses to report how frequently they shared decision making and leadership tasks with their partners, and made changes in their division of labor and in their approach to problems prior to illness onset. Now that one partner is no longer able to fulfill a marital role, greater adaptability may facilitate the healthy spouse's acceptance of changes in the marital relationship associated with dementia.

This interpretation is consistent with the finding that adaptability acted as a moderator of stress related to long hours spent in caregiving tasks. Adaptability, as it was measured here, may reflect the ability to make and accept changes in day to day routines or in marital roles and responsibilities. While coping with memory and behavior problems may require a good deal of flexibility, it also involves a loss of support and companionship from the marital partner as a result of the dementia symptoms. Adaptability may be less helpful in buffering this type of stress.

In fact, when hours of care were low, less adaptable caregivers experienced less depression than more adaptable caregivers. Perhaps caregivers in highly structured relationships valued order and a precise division of labor in their marriages. When hours of care were low and little change was required in daily routines, these caregivers may have experienced very little distress. In contrast, more

adaptable caregivers may place less emphasis on daily routine. Instead, they may experience distress related to other factors, such as the loss of companionship from the patient or the fear of future deterioration, and thus experience distress even when hours of care are low.

It is also possible that adaptability was related to changes in marital roles, but that the choice of spouse or caregiver role used in this study did not adequately assess these changes. Support groups, educational programs, and literature written for families of dementia patients all utilize the term "caregiver" and encourage families to accept the patient's illness. Spouses of more impaired patients may have adopted the label of caregiver despite some variability in their actual role in relation to the patient.

Adaptability is likely to represent only a small part of the stress-distress equation, but the data suggest that adaptability is nonetheless an important variable to consider. As a coping resource, adaptability may also be a factor in adjustment to other types of stressful situations, particularly those that involve changes in the structure of family or other close relationships such as the decision to institutionalize a spouse, accepting paid help into the home, moving to a senior residence or other assisted living situation, or having adult children move into or out of the home. These data raise intriguing questions about the

potential role of adaptability in the psychological adjustment of dementia caregivers; further research is needed to begin to address these issues.

Correlates of caregiver distress

It is also interesting that memory and behavior problems were directly related to caregiver burden and depression, while hours spent caregiving were not. This finding is consistent with some previous research (Schulz & Williamson, 1991) but at odds with another study that did not find a relationship between any aspect of patient impairment and caregiver burden (Zarit et al., 1980).

Although dementia presents caregivers with extensive concrete burdens and time constraints, it was cognitive decline and loss of "personhood" that many caregivers identified as the most difficult aspect of caring for their demented partners. "I miss his companionship. I don't have him to talk to anymore....We had a lot in common. He was a lover and a friend." "He was bright, alert, but everything falls away. There's nothing left but the body." One man clearly describes the distinction between the physical and emotional aspects of care: "I don't mind the work. It's the lack of communication and understanding. She was verbal and creative. Now she isn't there." In open-ended responses, many caregivers identified the loss of companionship, intimacy, and shared activities (socializing with friends, travel, cultural pursuits, conversation, sexual contact) as

the most difficult aspects of living with a spouse with dementia. Patients' bizarre behavior and memory impairment are the concrete manifestations of this loss of the patient as a person. It is not surprising that this aspect of the illness was associated with the greatest degree of psychological distress.

It is possible that the measures of caregiver burden and depression did not assess the aspects of caregivers' lives that were most affected by the physical demands of care. Poulshock and Deimling's (1984) work suggests that different caregiving stressors may be related to different caregiver outcomes. In this study, hours of care was significantly related to caregiver depression in zero-order correlations at the .10 level, but not in the regression analyses. The correlation with caregiver burden was only slightly smaller (r=.22 vs. .24), but not statistically significant). A measure of perceived stress or of the negative impact of caregiving on specific life domains may have been more strongly related to hours of care than the criterion measures used in this study.

Unlike a number of other caregiving studies, there were no gender differences in adaptability, role choice, hours of care provided, use of paid help, burden, depression, or cluster membership among caregivers in this sample. The absence of gender differences does not appear to be a function of limited statistical power, as scores on all

measures were virtually identical for men and women. Although previous research has documented differences among husbands and wives in their approach to care and predictors of distress, these findings are only small to moderate in magnitude and may be of limited practical significance (Miller & Cafasso, 1992).

Limitations of the research

A number of limitations of the research must be considered when interpreting the study findings. First, the sample size of 54 did not allow adequate power to detect small effect sizes if they were present in the data. For example, as just described, there may have been a relationship between hours of care and caregiver outcomes that was too small to be detected in multivariate analyses. To compensate for low power, findings were considered statistically significant at $p<.10$. Thus, the risk of a Type I error is higher than in research utilizing more stringent significance criteria.

A second limitation of the research is the generalizability of the findings. Caregivers in this sample were almost exclusively white, of moderate income and resided in the New York City metropolitan area. It is possible that the relationships among patient impairment, adaptability and caregiver outcomes might be different among other groups of caregivers, such as adult children or low income families.

Difficulties experienced in recruiting the sample raise further issues regarding generalizability. Over 120 agencies and private practices in the New York City metropolitan area were contacted regarding their clients' participation. Only a small subset of these actually referred clients to the study, and only a small number of participants were recruited from any one source. As it is impossible to know how many agencies actually disseminated information regarding the study to their clients, it cannot be determined if the problems in recruitment were the result of reluctance to participate on the part of agency personnel, caregivers, or both. Among agencies or practitioners who chose not to participate, or who distributed flyers but received limited response, reasons for refusal included: participation in one or more prior studies; few clients who met study criteria (spouses caring for a partner at home); concerns about confidentiality; conflict of interest with research being conducted by the agency. Whatever the reasons for refusal, the limited response rate raises the possibility that caregivers who were asked to participate, or who agreed to participate, were unique in some way.

However, the fact that a wide range of patient impairment, hours devoted to caregiving, burden, and depression were represented in the sample, and that mean levels of patient impairment, burden, and depression were

comparable to those found in other studies of caregiving spouses, gives some indication that the sample was not biased toward caregivers who were more distressed or caring for a more or less severely impaired partner. The diversity of sources, which included both urban and suburban populations, further enhanced the generalizability of the data.

The third and possibly most important limitation of the research is related to the measurement of the construct of adaptability. Of necessity, adaptability was measured retrospectively, as caregivers could only be identified for inclusion in the research after their partners became ill. These retrospective accounts must be interpreted with some caution, as they may have been colored by the changes in the relationships between spouses and patients that were brought about by the illness. However, adaptability was not related to time since the onset of dementia symptoms, nor to time since diagnosis. This offers some reassurance that there was no systematic bias related to the length of time that spouses were providing care to their partners with dementia.

Adaptability was measured using only the self-reports of one member of the couple, the caregiving spouse, as it was not possible to obtain the input of the spouse with dementia. It must be kept in mind that the other spouse's perceptions of adaptability within the relationship may have been different. Future studies should include behavioral

measures to validate the self-report adaptability subscale. A potential validity measure might include questions about specific behaviors related to transitional events in the couple's life, such as moving, retirement, or job changes.

Reliability of the adaptability scale was adequate but not high (alpha=.68), suggesting that measurement error may have attenuated the magnitude of statistical relationships between adaptability and other variables. Despite low reliability, a buffering effect of adaptability on caregiving stress was detected for the outcome of caregiver depression. However, other effects of adaptability may have been evident had reliability been better.

Another issue related to the measurement of adaptability is a possible confound with beliefs in traditional sex roles. Two of the ten items address the division of labor in household chores ("We shifted household responsibilities from person to person," "It was hard to tell who did which household chores") and two directly refer to leadership roles within the marriage ("It was hard to identify who the leader was in our relationship," and "Different people acted as leaders in our marriage"). In fact, 70.5% of the sample reported that they never shifted household responsibilities, and 88.9% of the sample indicated that they always knew who was responsible for household chores. There was somewhat greater variability in responses to questions about leadership roles within the

relationship; however, 64.8% believed that it had never been hard to identify the leader in their marriages.

In open-ended questions, many caregivers described difficulties in taking on unfamiliar roles when the patient was no longer able to fulfill them. Men spoke of being overwhelmed by unaccustomed housework and cooking, women by decision-making and financial management. It is possible that the elevated levels of depression experienced by caregivers low in adaptability who were also providing many hours of care may be related to performance of more tasks outside accustomed gender roles. Such traditionalism may be unique to the current cohort of elderly people; as cohorts who hold more egalitarian sex role beliefs age, they may bring very different coping resources and styles to bear on the stressors accompanying aging and declining health.

The combination of low adaptability and the choice of a spouse role despite severe patient impairment among the cluster of Rigid Spouses may also reflect sex-role traditionalism. Having entered into marriage as a lifetime commitment, these spouses may be unable to acknowledge the change in their situation, or may consider caregiving to be an expected part of the spouse role at this life-stage.

Another interesting possibility to consider is that traditionalism is not a confound in the measurement of adaptability, but rather a component of the construct. It is possible that holding rigid ideas about the roles that

men and women should take is related to a more global inflexibility. If this were the case, future cohorts may exhibit greater flexibility in all areas, enhancing their ability to cope with the stresses of aging.

Despite these limitations, this study is part of a growing body of work considering the structure of the relationship between caregiver and patient. Most prior studies have considered the caregiving situation in a vacuum, ignoring the context of a relationship that has evolved over many years. This broader focus is needed to further our understanding of the nature of caregiving relationships and the impact of this stressor on family members.

Implications of these findings for service providers

What are the practical implications of these findings for those who provide medical or social services to dementia caregivers? These data suggest that less adaptable spouses may have more difficulty adjusting to the stress of caregiving, especially when they must provide long hours of care, or when they are providing care to patients with severe impairment in a number of areas. Less adaptable caregivers may have particular problems in adjustment when they are caring for a severely impaired partner, but continue to endorse a spouse role in relation to the patient.

Accepting change, both in patients' functioning and

behavior and in their own relationship with the patient, is one of the primary coping tasks that dementia caregivers face. Service providers should be sensitive to caregivers' coping styles, and try to identify caregivers who may be having trouble coming to terms with the losses inherent in a diagnosis of dementia. Less adaptable caregivers may need additional help as the patient's condition deteriorates, and may be at higher risk for depression. In counseling caregivers, providers could stress the importance of accepting inevitable changes in patients' mental and physical abilities, and encourage caregivers to develop greater flexibility in their approach to patient care and in their expectations of patients' behavior.

Service providers should also be aware that memory and behavior problems appear to be the most difficult aspect of the illness for many spouse caregivers to handle. Caregivers may need help in developing strategies to better understand and more effectively cope with patients' memory and behavioral problems. Time away from the patient, through adult day care programs or periodic respite care, may also help alleviate the burden of patients' behavioral problems.

Finally, services designed to minimize the physical burdens of care, such as providing a home attendant, may not fully address the most burdensome aspects of the illness for all caregivers. Physical assistance with caregiving may be

more helpful for less adaptable caregivers, who seem to experience greater difficulty when more hours of care are required. This is not to say that more flexible spouses did not find home attendant services helpful - every caregiver who utilized paid assistance spoke of how important these services were to them, as it enabled them to rest or to take more time for themselves. Many caregivers saw paid help as a way to prolong their ability to provide care for their spouse at home and avoid institutionalization. Rather, the data suggest that individual caregivers may have very different service needs, and will often require a combination of services designed to address the aspects of caregiving most difficult for them.

Implications for future research

As discussed above, this study raises a number of questions regarding the role of adaptability in spouses' adjustment to the stresses of caregiving, as well as the broader implications of the findings for other research on adjustment to stress. Will the finding of a moderator effect for adaptability be replicated with other larger or more representative samples of caregiving spouses? Is adaptability important for other family caregivers, such as adult children, who do not face changes in their primary supportive relationship as a result of the dementia?

The findings of the cluster analysis -- that the combination of severe impairment, low adaptability and

endorsement of a spouse role are related to greater caregiver depression -- provokes a number of new research directions. Longitudinal research might investigate the stage of the illness at which caregiving spouses must relinquish a spouse role and adopt a caregiver role, and the part that adaptability plays in this process. Do spouses who are low in adaptability have difficulty restructuring their marital role relationships even when their partner is severely impaired?

Research focussing on transition points in the caregiving relationship, such as initial diagnosis, the entry of outside help into the home, or institutional placement of the patient, could shed more light on the process of adaptation to chronic stress. This would provide the opportunity to test the importance of adaptability related to specific changes in the relationship between caregiver and patient. Does adaptability serve as a resource in helping spouses adjust to the diagnosis of dementia? Or is adaptability more important later on in the course of the illness, as spouses must come to terms with patients' progressive mental deterioration? Does greater adaptability allow spouses to make changes in their caregiving routine, such as hiring a home health aide, that could help to alleviate feelings of captivity in the caregiver role (Aneshensel et al., 1993) and delay institutional placement? When spouses are no longer able to

provide care at home, does greater adaptability help spouses to adjust to patients' nursing home placement?

Before any of these studies can be carried out, a better understanding of the construct of adaptability and its measurement is needed. Is adaptability restricted to the tendency of couples or families to change their organizational structure in response to new situations, or does it reflect a broader tendency to adapt to situational changes on an individual level? Is adaptability a factor in individual and family adjustment to other types of stressful situations, such as coping with the changes brought about by physical illness or financial difficulties?

On a broader level, the findings of this study highlight the importance of considering caregivers' characteristic styles of coping with stress and change, as well as the need to study coping within the broader context of the relationship between patient and caregiver. Research on family caregiving must move in a new direction, considering the dynamic nature of family relationships. Studies focussing simply on the stress and burden of caregiving do not present an adequate or accurate picture. To fully capture the richness of family relationships, caregiving research must expand its focus to include the longstanding interpersonal ties that motivate and sustain family care.

Appendix A

Consent forms

CARING FOR A SPOUSE WITH DEMENTIA STUDY

CONSENT FORM

This research is being conducted by Deborah Majerovitz, a doctoral candidate of the Program in Psychology at the Graduate School and University Center of the City University of New York under the supervision of Professor Tracey Revenson. It is a study of the caregiving experiences of husbands and wives of people with dementia.

Participation in the study involves:

1. A brief test of your spouse's memory, conducted in your home.

2. One interview centering on you caregiving experiences, conducted in your home.

Participation in this study is **voluntary** and all information you give will be kept strictly **confidential.** Your name will never be used. You are identified only by a code number printed on the cover of your interview booklet. You may choose not to answer any question. However, it is important to try to answer each question.

If you have any questions regarding this research, you can call Deborah Majerovitz at 212-642-2524, or Professor Tracey Revenson at 212-642-2534. If you have any questions concerning your rights as a participant in this study, you can call the Office of Sponsored Research, City University of New York, at 212-642-2059.

Before you begin the interview, please sign below. This page will be stored separately from your interview responses.

I voluntarily consent to participate in this study, having read and fully understood the description of the study and its procedures, and of my rights as a participant. I further give my consent for my spouse to participate in the study if he or she is unable to understand this form or to sign it him or herself.

_____ _____

Signature Signature of interviewer

CARING FOR A SPOUSE WITH DEMENTIA STUDY

CONSENT FORM

This research is being conducted by Deborah Majerovitz, a doctoral candidate of the Program in Psychology at the Graduate School and University Center of the City University of New York under the supervision of Professor Tracey Revenson. It is a study of the caregiving experiences of husbands and wives of people with dementia.

Your participation in the study involves only a brief test of your memory conducted in your home.

Participation in this study is **voluntary** and all information you give will be kept strictly **confidential.** Your name will never be used. You are identified only by a code number printed on the cover of your interview booklet. You may choose not to answer any question. However, it is important to try to answer each question.

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Before you begin the interview, please sign below. This page will be stored separately from your interview responses.

I voluntarily consent to participate in this study, having read and fully understood the description of the study and its procedures, and of my rights as a participant.

_____ _____

Signature Signature of interviewer

Appendix B.

Questionnaire

MARRIAGE AND CAREGIVING

ID_____ **Date** _____

Interviewer _____ **Time** _____ **am pm**

Sex of participant M F

First, I'd like to ask you a few background questions about you and your spouse

1. Your date of birth: _____

2. Your spouse's date of birth: _____

3. Your religion:

1. Protestant 2. Catholic 3. Jewish
4. Moslem 5. No religion 6. Other _____

4. Your spouse's religion:

1. Protestant 2. Catholic 3. Jewish
4. Moslem 5. No religion 6. Other _____

5. Your race/ethnic background:

1. African-American 2. Asian 3. Hispanic
4. White 5. Other _____

6. Your spouse's race/ethnic background:

1. African-American 2. Asian 3. Hispanic
4. White 5. Other _____

7. Your occupational status:

1. Employed full time 2. Employed part time
3. Retired 4. Homemaker 5. Unemployed

8. Total family income for 1991:

1. Under $10,000 2. $10-20,000 3. 21-30,000
4. 31-50,000 5. $51-70,000 4. Above $70,000

9. Highest year of school you completed:

1. 8 years or less 2. 9-11 years
3. High school graduate 4. Some college
5. College graduate 6. Grad/professional school

10. Highest year of school your spouse completed:

1. 8 years or less 2. 9-11 years
3. High school graduate 4. Some college
5. College graduate 6. Grad/professional school

11. Year married 19_____

12 Do you and your spouse have any children together?
Yes No

13. How many children do you have? _____

14a. Are they sons or daughters?		14b. Do they live within 2 hours drive?	
Son	Daughter	Yes	No
Son	Daughter	Yes	No
Son	Daughter	Yes	No
Son	Daughter	Yes	No
Son	Daughter	Yes	No
Son	Daughter	Yes	No

15. Is this your first marriage? Yes No

16. Is this your spouse's first marriage?
(If YES to 15 and 16, skip to 19) Yes No

17. Do you have children from a previous marriage?
Yes No

18a. Whose children		18b. Sons/daughters?		18c. Live within 2 hrs. drive	
Self	Spouse	Son	Daughter	Yes	No
Self	Spouse	Son	Daughter	Yes	No
Self	Spouse	Son	Daughter	Yes	No
Self	Spouse	Son	Daughter	Yes	No
Self	Spouse	Son	Daughter	Yes	No
Self	Spouse	Son	Daughter	Yes	No

19. Does anyone live with you besides your spouse? Who?

Relationship to you	Age	Sex
_____	_____	M F
_____	_____	M F
_____	_____	M F

20. How would you describe your own health, compared to others your age?

1. Excellent 2. Good
3. Fair 4. Poor

21. Apart from the dementia, does your spouse suffer from any chronic physical illnesses?

1. No 2. Yes What are they? _____

HISTORY OF THE DEMENTIA

Now I'd like you to think back to the time that you first noticed that your spouse might be ill.

22. How long ago did you first notice symptoms of dementia?

1. Within the past year 2. 1-3 years ago
2. 3-5 years ago 3. 5-7 years ago
4. 7-10 years ago 5. More than 10 yrs. ago

22a. What were the first symptoms that you noticed?

23. How long after you noticed these symptoms did you and your spouse first consult a doctor regarding your spouse's symptoms?

1. Within 1 month 2. Within 6 months
3. Within 1 year 4. Within 2 years
5. Longer than 2 years afterwards

24. How long ago did your spouse first receive a definite diagnosis related to the dementia?

1. Within the past year 2. 1-3 years ago
2. 3-5 years ago 3. 5-7 years ago
4. 7-10 years ago 5. More than 10 yrs. ago

25. What is that diagnosis? _____

SOCIAL SUPPORT

Next, I'm going to ask you some questions about the amount of help that is available to you as you care for your spouse.

1. Who helps you DIRECTLY in taking care of your spouse (for example, feeding your spouse or watching him/her so you can go out, etc.)? How often do they help you?

Relationship	Sex	How often?			
_____	M F	Daily	Weekly	Monthly	Less often
_____	M F	Daily	Weekly	Monthly	Less often
_____	M F	Daily	Weekly	Monthly	Less often
_____	M F	Daily	Weekly	Monthly	Less often
_____	M F	Daily	Weekly	Monthly	Less often
_____	M F	Daily	Weekly	Monthly	Less often

2. Do you have any paid help in taking care of your spouse? Yes No

3. If so, how often and for how long per visit? _____

4. How many people can you count on to provide other kinds of help or emotional support (not related to the care of your spouse) when you need it?

0 1 2 3 4 5 6 7 8 9 10

TIME SPENT IN CAREGIVING

1. Thinking about all the things you do in caring for your spouse, how many hours per day do you spend providing direct care to your spouse? Direct care includes everything you do for your spouse, such as helping your spouse to eat, bathe or dress, supervising you spouse so that he/she does not get lost or do something potentially harmful, cleaning up after your spouse, keeping your spouse busy, etc.

1. Less than 2 hours/day
2. 2-4 hrs/day
3. 4-6 hrs/day
4. 6-8 hrs/day
5. 8-10 hrs/day
6. 10-12 hrs/day
7. 12-14 hrs/day
8. 14-16 hrs/day
9. 16-18 hrs/day
10. More than 18 hrs/day

FAMILY ROLES

Next, I'm going to ask some questions about the different kinds of things you do for your spouse. Each couple may find different aspects of the marital relationship to be more important to them at different times. When you hear each statement, please think about how important it is <u>to you NOW</u> to do each of these things for your spouse. For each one, tell me if you think it is:

1. Not at all important
2. A little important
3. Somewhat important
4. Very important

1.	Being a companion for your spouse.	1	2	3	4
2.	Being involved in your spouse's medical care.	1	2	3	4
3.	Doing things together for pleasure or relaxation	1	2	3	4
4.	Protecting your spouse from harm.	1	2	3	4
5.	Making sure your spouse is clean and well cared for.	1	2	3	4
6.	Being there for your spouse to confide in.	1	2	3	4
7.	Having a conversation with your spouse.	1	2	3	4
8.	Making sure your spouse is physically comfortable.	1	2	3	4

9. Finally, if you had to choose <u>one phrase</u> to describe your role right now, which of the following would come closest?

   1. I am the wife/husband of a person with dementia.
   2. I am the caregiver for a person with dementia.

CAREGIVING ACTIVITIES

The next set of questions deals with the amount of help your spouse needs with personal care and daily activities. For each one, please choose the answer that best describes how much help your spouse currently needs.

ACTIVITIES OF DAILY LIVING:

A. Toilet

1. Cares for self at toilet completely, no incontinence.
2. Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most) accidents.
3. Soiling or wetting while asleep more than once a week.
4. Soiling or wetting while awake more than once a week.
5. No control of bowels or bladder.

B. Feeding.

1. Eats without assistance.
2. Eats with minor assistance at meal times and/or with special preparation of food, or help in cleaning up after meals.
3. Feeds self with moderate assistance and is untidy.
4. Requires extensive assistance for all meals.
5. Does not feed self at all and resists efforts to feed him/her.

C. Dressing.

1. Dresses, undresses, and selects clothes from own wardrobe.
2. Dresses and undresses self, with minor assistance.
3. Needs moderate assistance in dressing or selection of clothes.
4. Needs major assistance in dressing, but cooperates with efforts of others to help.
5. Completely unable to dress self and resists efforts of others to help.

D. Grooming (neatness, hair, nails, hands, face, clothing).

1. Always neatly dressed, well-groomed, without assistance
2. Grooms self adequately with occasional minor assistance, e.g. shaving.
3. Needs moderate and regular assistance or supervision in grooming.
4. Needs total grooming care, but can remain well-groomed after help from others.
5. Actively negates all efforts of others to maintain grooming.

E. Physical Ambulation.

1. Goes around neighborhood or city.
2. Ambulates within residence or about one block distance.
3. Ambulates with assistance of (circle one)
   a. another person b. railing
   c. cane d. walker
   e. wheelchair:
      e1. gets in/out without help
      e2. needs help getting in/out

F. Bathing.

1. Bathes self (tub, shower, sponge bath) without help.
2. Bathes self with help in getting in/out of tub.
3. Washes face and hands only, but cannot bathe rest of body.
4. Does not wash self but is cooperative with those who bathe him/her.
5. Does not try to wash self and resists efforts to keep him/her clean.

INSTRUMENTAL ACTIVITIES OF DAILY LIVING

A. Ability to Use Telephone.

1. Operates telephone on own initiative, looks up an dials numbers, etc.
2. Dials a few well-known numbers.
3. Answers telephone but does not dial.
4. Does not use telephone at all.

B. Shopping.

1. Takes care of all shopping needs independently.
2. Shops independently for small purchases.
3. Needs to be accompanied on any shopping trip.
4. Completely unable to shop.

C. Food Preparation.

1. Plans, prepares and serves adequate meals independently.
2. Prepares adequate meals if supplied with ingredients.
3. Heats and serves prepared meals; or prepares meals but does not maintain adequate diet.
4. Needs to have meals prepared and served.

D. Housekeeping.

1. Maintains house alone or with occasional assistance for heavy work.
2. Performs light daily tasks such as dishwashing bedmaking.
3. Performs light daily tasks, but cannot maintain acceptable level of cleanliness.
4. Needs help with all home maintenance tasks.
5. Does not participate in any housekeeping task.

E. Laundry.

1. Does personal laundry completely.
2. Launders small items; rinses socks, stockings, etc.
3. All laundry must be done by others.

F. Mode of Transportation.

1. Travels independently on public transportation or drives own car.
2. Arranges own travel via taxi, but does not otherwise use public transportation.
3. Travels on public transportation when assisted or accompanied by another.
4. Travel limited to taxi or automobile with assistance of another.
5. Does not travel at all.

G. Responsibility for Own Medications.

1. Is responsible for taking medication in correct dosage at correct time.
2. Takes responsibility if medication is prepared in advance in separate dosages.
3. Is not capable of dispensing own medication.

H. Ability to Handle Finances.

1. Manages financial matters independently; budgets, writes checks, pays rent, bills, goes to bank, collects and keeps track of income.
2. Manages day to day purchases, but needs help with banking, major purchases, etc.
3. Incapable of handling money.

MEMORY AND BEHAVIOR PROBLEMS

The following questions refer to problems in memory and behavior that people with dementia often experience. For each problem listed below, please tell me how often your spouse engages in the behavior using the following choices.

0. Never
1. Occurred frequently in the past but not in the past three months.
2. Has occurred recently, but not in the past week.
3. 1 or 2 times in the past week.
4. 3 to 6 times in the past week.
5. Daily or more often.
7. Does not occur because of my supervision.

1.	Asking the same question over and over.	0	1	2	3	4	5	7
2.	Trouble remembering recent events.	0	1	2	3	4	5	7
3.	Trouble remembering significant events from the past.	0	1	2	3	4	5	7
4.	Mixing up past and present (e.g. thinking a deceased parent is still alive).	0	1	2	3	4	5	7
5.	Losing or misplacing things.	0	1	2	3	4	5	7
6.	Hiding things.	0	1	2	3	4	5	7
7.	Unable to find way about indoors.	0	1	2	3	4	5	7
8.	Unable to find way about outdoors, for example on familiar streets.	0	1	2	3	4	5	7
9.	Wandering or getting lost.	0	1	2	3	4	5	7
10.	Not recognizing a familiar place.	0	1	2	3	4	5	7
11.	Not recognizing familiar people.	0	1	2	3	4	5	7
12.	Not recognizing a familiar object.	0	1	2	3	4	5	7
13.	Forgetting what day it is.	0	1	2	3	4	5	7
14.	Unable to start activities by self (not ADLs)	0	1	2	3	4	5	7

15.	Unable to keep occupied or busy by self.	0	1	2	3	4	5	7
16.	Follows you around.	0	1	2	3	4	5	7
17.	Being constantly restless or agitated.	0	1	2	3	4	5	7
18.	Spending long periods of time inactive.	0	1	2	3	4	5	7
19.	Being constantly talkative.	0	1	2	3	4	5	7
20.	Talking little or not at all.	0	1	2	3	4	5	7
21.	Being suspicious or accusative.	0	1	2	3	4	5	7
22.	Doing things in public that are socially inappropriate or embarrassing to you.	0	1	2	3	4	5	7
23.	Waking you up at night.	0	1	2	3	4	5	7
24.	Appears sad or depressed.	0	1	2	3	4	5	7
25.	Appears anxious or worried.	0	1	2	3	4	5	7
26.	Becomes angry.	0	1	2	3	4	5	7
27.	Strikes out or tries to hit.	0	1	2	3	4	5	7
28.	Destroying property	0	1	2	3	4	5	7
29.	Engaging in behavior that is potentially dangerous to others or self.	0	1	2	3	4	5	7
30.	Seeing or hearing things that are not there.	0	1	2	3	4	5	7
31.	Are there any other memory or behavior problems that I did not mention?	0	1	2	3	4	5	7
32.	Other (second problem).	0	1	2	3	4	5	7

PERSONAL FEELINGS

Next, I'm going to ask questions relating to your feelings about caregiving and about yourself. For each question, please tell me how often you feel that way using the following choices:

0. Never
1. Rarely
2. Sometimes
3. Quite Frequently
4. Nearly Always

1.	Do you feel that your spouse asks for more help than he/she needs?	0	1	2	3	4
2.	Do you feel that because of the time you spend with your spouse that you don't have enough time for yourself?	0	1	2	3	4
3.	Do you feel stressed between caring for your spouse and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4.	Do you feel embarrassed over your spouse's behavior?	0	1	2	3	4
5.	Do you feel angry when you are around your spouse?	0	1	2	3	4
6.	Do you feel that your spouse currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7.	Are you afraid of what the future holds for your spouse?	0	1	2	3	4
8.	Do you feel your spouse is dependent upon you?	0	1	2	3	4
9.	Do you feel strained when you are around your spouse?	0	1	2	3	4
10.	Do you feel your health has suffered because of your involvement with your spouse?	0	1	2	3	4
11.	Do you feel that you don't have as much privacy as you would like because of your spouse.	0	1	2	3	4

12.	Do you feel that your social life has suffered because you are caring for your spouse?	0	1	2	3	4
13.	Do you feel uncomfortable about having friends over, because of your spouse?	0	1	2	3	4
14.	Do you feel that your spouse seems to expect you to take care of him/her, as if you were the only one he/she could depend on?	0	1	2	3	4
15.	Do you feel that you don't have enough money to care for your spouse,in addition to the rest of your expenses?	0	1	2	3	4
16.	Do you feel that you will be unable to care for your spouse much longer?	0	1	2	3	4
17.	Do you feel that you have lost control of your life since your spouse's illness?	0	1	2	3	4
18.	Do you wish you could just leave the care of your spouse to someone else?	0	1	2	3	4
19.	Do you feel uncertain about what to do about your spouse?	0	1	2	3	4
20.	Do you feel you should be doing more for your spouse?	0	1	2	3	4
21.	Do you feel you could do a better job in caring for your spouse?	0	1	2	3	4

22. Overall, how burdened do you feel in caring for your spouse?

0. Not at all 1. A little 2. Moderately
3. Quite a bit 4. Extremely

For each of the following questions, tell me how often you have been feeling that way DURING THE PAST WEEK using the following choices:

0. Rarely: Less than 1 day during the past week.
1. Some of the time: 1-2 days during the past week.
2. Occasionally: 3-4 days during the past week.
3. Most of the time: 5-7 days during the past week.

1.	I was bothered by things that don't usually bother me.	0	1	2	3
2.	I did not feel like eating; my appetite was poor.	0	1	2	3
3.	I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
4.	I felt that I was just as good as other people.	0	1	2	3
5.	I had trouble keeping my mind on what I was doing.	0	1	2	3
6.	I felt depressed.	0	1	2	3
7.	I felt that everything I did was an effort.	0	1	2	3
8.	I felt hopeful about the future.	0	1	2	3
9.	I thought my life had been a failure.	0	1	2	3
10.	I felt fearful.	0	1	2	3
11.	My sleep was restless.	0	1	2	3
12.	I was happy.	0	1	2	3
13.	I talked less than usual	0	1	2	3
14.	I felt lonely.	0	1	2	3
15.	People were unfriendly.	0	1	2	3
16.	I enjoyed life.	0	1	2	3
17.	I had crying spells.	0	1	2	3
18.	I felt sad.	0	1	2	3
19.	I felt that people disliked me.	0	1	2	3
20.	I could not get "going".	0	1	2	3

FAMILY RELATIONSHIPS

This next set of questions is the next-to-last, so we're almost at the end! As you answer these questions, I would like you to think back to the time before your spouse had any symptoms of dementia. When you answer each question, tell me about the way things were done in your family BEFORE YOUR SPOUSE'S ILLNESS. I know that you may do things differently now, but I'd like you to answer each question thinking about the way you did things before. To describe your relationship before your spouse's illness, please use the following choices:

1. Almost never
2. Once in a while
3. Sometimes
4. Frequently
5. Almost always

1.	When problems arose, we compromised.	1	2	3	4	5
2.	We were flexible in how we handled our differences.	1	2	3	4	5
3.	Different persons acted as leaders in our marriage.	1	2	3	4	5
4.	We changed our way of handling tasks.	1	2	3	4	5
5.	We tried new ways of dealing with problems.	1	2	3	4	5
6.	We jointly made the decisions in our marriage.	1	2	3	4	5
7.	Rules changed in our marriage.	1	2	3	4	5
8.	We shifted household responsibilities from person to person.	1	2	3	4	5
9.	It was hard to identify who the leader was in our marriage.	1	2	3	4	5
10.	It was hard to tell who did which household chores.	1	2	3	4	5

FINAL QUESTIONS

Now, I'd like to ask you a few final questions that will give you a chance to expand more on your feelings and experiences as a caregiver.

1. For you, what is the worst thing about caring for your spouse?

2. What positive things has caring for your spouse brought you? These can be related to your feelings, your relationship with your spouse or other people, how you see yourself, or any other area of your life.

3. What advice would you give to other caregivers to make the process easier for them?

4. Is there anything you would like to add that has not been covered in the interview?

5. Do you have any questions about what we discussed in the interview?

MINI MENTAL STATE EXAM ID# _____

Points			Score
	ORIENTATION		
3	a.	**What is today's date?** _____ (Prompt for any missing parts - e.g. What year/month/date is it? Give one point for each part of the date that is correct).	_____
1	d.	**What day of the week is it?** _____	_____
1	e.	**Can you also tell me what season it is?** _____	_____
1	f.	**Where are we now?** _____	_____
1	g.	**What state are we in?** _____	_____
1	h.	**What county are we in?** _____	_____
1	i.	**What city are we in?** _____	_____
1	j.	**What is your address?** _____	_____
	REGISTRATION	**Next, I'm going to test your memory. Remember these words.** (say them slowly) **APPLE DOG TABLE**	
3		**Repeat the three words for me.** (Score 1 point for each correct on the first trial) (Now, you are going to teach the three words to the patient. Repeat this process until he/she can accurately repeat all three back to you. COUNT THE NUMBER OF TRIALS and record.) Number of trials _____	_____
	ATTENTION AND CALCULATION		
5	a.	**Count backwards from 100 by sevens.** (Stop the patient after 5: 93,86,79,72,65)	_____
	b.	(If patient cannot count by sevens, note this and try): **Please spell "WORLD" backwards.** (DLROW) Score one point per letter in correct order.	
	RECALL		
3		**Do you remember the three words you learned before? What were they?** (Score 1 point for each word recalled)	_____

LANGUAGE

1 a. (Show the patient a pencil.)
What is this called? _____

1 b. (Show the patient a watch.)
What is this called? _____

1 c. **Please repeat the following words after me: "NO IFS, ANDS OR BUTS"** _____

3. d. (Place a piece of paper in front of the patient). **Please follow my directions. "Take the paper in your right hand, fold it in half, and put it on the floor."** (Give 1 point for each of 3 directions followed) _____

1 e. **Please read and obey these directions.** (Give the patient a piece of paper with the words CLOSE YOUR EYES written on it). (Score 1 point only if patient closes eyes). _____

1 f. **Write a sentence on this piece of paper. The sentence can be about anything you like.** (Hand patient piece of paper. Score 1 point if sentence makes sense, has a subject and a verb. Grammar or punctuation not important. _____

1. g. (Hand patient the geometric figure). **Copy this design.** (Score one point if figure has all 10 angles and 2 intersect. Size, rotation of the figure or quality of the drawing do not matter). _____

TOTAL SCORE _____

LEVEL OF CONSCIOUSNESS

Assess the patient's level of consciousness during the interview. Use the following definitions: **ALERT:** Fully awake, aware of surroundings and able to participate in the interview; **DROWSY:** Awake and able to answer, but seems lethargic, unable to sustain participation without prompting; **STUPOR:** Awake, but completely unresponsive; **COMA:** Bedbound, not awake, completely unresponsive.

Circle one: Alert Drowsy Stupor Coma

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