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Men who are caregivers of cognitively impaired wives

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MEN WHO ARE CAREGIVERS OF COGNITIVELY IMPAIRED WIVES:
BECOMING EMBEDDED IN THE ROLE

by

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ABSTRACT

MEN WHO ARE CAREGIVERS OF COGNITIVELY IMPAIRED WIVES:
BECOMING EMBEDDED IN THE ROLE

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University of California, San Francisco, 1991

The aim of this research was to examine and describe the experience of husbands who become caregivers of cognitively impaired wives. The purpose of the study was to discover the process by which men become aware of themselves as caregivers, the strategies they use in maintaining the role, and the consequences to them of the caregiving experience. This exploratory study used grounded theory methodology as the approach to data analysis. Data were obtained from in-depth interviews with 15 older white male spouses who had been caregivers of cognitively impaired wives for a period of at least one year. Subjects were interviewed for 2-3 hours using a semi-structured interview guide. Questions were asked relating to how subjects became aware that they were caregivers, what changes occurred in their lives and relationships because of caregiving, who they relied upon to help them with caregiving, and the meaning the experience had for them.

Data analysis revealed that caregiving necessitated a major role transition for these men. Becoming embedded in the caregiver role was a gradual process that began with attempts by husbands to normalize functional and cognitive

changes in their wives and proceeded to recognition that they were totally responsible for the care and well-being of their spouses. Once embedded, husbands did not relinquish the role until their spouses died. Men became aware of themselves as caregivers when they could no longer normalize changes in their wives, when they recognized that they were assuming functions belonging to their wives, or when their wives were diagnosed with an illness that the husbands perceived as requiring a caregiver.

These caregivers received very limited support from family, friends, or formal service providers and were forced to become self-reliant in providing care for their wives. For most husbands in this group, becoming embedded in caregiving meant becoming embedded in a present that was tightly circumscribed by the needs of their impaired wives. They were forced to abandon plans that they had made for the future and were able to reclaim or reconstruct their futures only after their spouses died.

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CHAPTER 1

INTRODUCTION

Statement of the Problem

It is widely assumed in this culture that men, because of traditional sex role socialization, have neither the previous nurturing experience that is part of the early training of women nor the desire to develop caring and nurturing qualities. In the early phases of this study, I commonly encountered the belief that men are poor caretakers and, if given the opportunity, will abandon the care of dependent relatives to others. As one physician put it succinctly, "Why do you want to study men? They're such lousy caregivers." A social worker commented that in her experience men usually leave after a few months of being faced with the care of an ill spouse.

There are doubtless men who cannot or will not assume the role of caregiver, but there are also men who take on the burden of caring with the greatest devotion. It was a number of these men, described by Kaye and Applegate (1990) as "unsung heroes," who told with great poignancy of their struggles to cope with everyday problems as well as deeper issues of loss and change in their lives as they cared for their impaired wives.

This study sought to examine and describe the experience of men who become caregivers of cognitively impaired wives. The purpose of the research was to discover

the process by which they become aware of themselves as caretakers, the strategies they use in maintaining the role, and the consequences to them of the caregiving experience.

Significance of the Problem

One of the principal findings to emerge from the upsurge of interest in community care of old people in the last two decades is that families do not easily relinquish their perceived obligations to frail and impaired elderly members. The pervasive social myth that old people are alienated from their families and rejected by their children has been debunked by a growing body of research (Shanas, 1979) as have several related fables: that families "dump" elderly relatives into institutions, that formal support services provide the bulk of care to the dependent elderly, and that availability of formal services encourages families to shirk responsibility to aged members (Brody, 1981). Although "long-term care" has become a major concern of government and a growing industry in the United States, Brody (1985) points out that families long ago invented long term care with less fuss, more willingness, and more effectiveness than the health care bureaucracy. The growing realization that, in an aging America, numbers of functionally and mentally impaired old people will steadily increase has prompted a corresponding interest family caregivers: Who are they? What is it that they do, and how does it affect them? Can they be helped to do it better and

longer? It is recognized that family support is the single most crucial factor in maintaining impaired elderly people in the community (Brody, Poulshock, & Masciocchi, 1978; Gilhooly, 1984b). As the costs of institutional care escalate, family caregiving has become a significant national resource.

Research consistently shows that family members who care for elderly cognitively impaired relatives suffer enormous stress (Gilleard, 1984). Gilhooly (1984b) found that caregivers of mentally impaired individuals often volunteered the perception that caring for a physically ill person, no matter how ill, would be less difficult.

Dementing illnesses of the elderly are now recognized to be among the major public health problems of this, and perhaps the next, century. These disorders are a significant cause of dependency and disability in the aged. In 1980 it was estimated that 15% of persons in the United States aged 65 or above (3.8 million) suffered from some form of dementia. More than half of this group, about 2 million cases, were believed to have Alzheimer's Disease, which is progressive, incurable, and peculiarly age-related. More recent estimates place the number of Alzheimer victims at nearly 3 million (Thal, 1988).

By the year 2000 it is estimated that 12.6% of the nation's population, approximately 35 million people, will be over age 65 (U. S. Bureau of the Census, 1990). The most consequential increase in numbers of elderly persons is projected to be among the group that is aged 85 and above (Kaye & Applegate, 1990). When people live into very old age, the incidence of dementing illness rises sharply (Gilleard, 1984). As America ages the number of individuals in the vulnerable age group, for whom some degree of chronic illness, disability, and dependency is likely, will increase dramatically (Kaye & Applegate, 1990).

While more than 50% of elderly persons in long term care facilities suffer from cognitive impairment, the vast majority of demented persons are maintained in the community and cared for at home (Zarit, Reever, & Bach-Peterson, 1980). Although there is much interest in the concept of "community care" and "informal networks" for the infirm elderly, the reality is that most care and supervision is provided by family members and, most often, by one primary supporter who assumes responsibility for the impaired person (Gilleard, 1984).

For a number of reasons, both cultural and demographic, the majority of caregivers are women. Women tend to marry men older than themselves, which makes it likely that they will at some time care for a disabled husband. Traditional role expectations of women also make them the preferred caretakers of both young and old dependents. However, changes in modern family structure have reduced the availability of women for caregiving. The trend toward

smaller families means fewer potential caregivers for elderly members (Kaye & Applegate, 1990). Greater mobility of families increases the likelihood that some members will be geographically unavailable to act as supporters. Moreover, economic necessity as well as increasing acceptance of the needs of women to pursue personal and career goals have propelled women into the workplace and left them less free for caregiving. Not surprisingly, therefore, increasing numbers of men have begun to accept the role of caregiver (Kaye & Applegate, 1990). As demonstrated by recent studies, men now constitute a sizeable minority, about one third, of those who are caring for aged family members. The majority of these men are spouses (Cantor, 1983; Kaye & Applegate, 1990; Scott, Roberto, & Hutton, 1986; Zarit, Todd, & Zarit, 1986).

Despite the growing realization that caregivers cannot be regarded merely as a "homogeneous" group consisting primarily of female relatives, researchers often have not recognized that different caregiver groups may have distinctly different experiences. Study samples have generally been heavily weighted with female subjects, with the result that research findings may also reflect primarily the experience of women. The tendency of researchers and health policy makers to ignore differences has obscured the dynamics of caregiving as it relates to specific groups (Cantor, 1983). Studies which explore caregiving by men can provide conceptual perspectives that explicate their experience and assist in the development of appropriate strategies to assist them.

CHAPTER 2

REVIEW OF RELATED LITERATURE

Much of the research on family caregiving of cognitively impaired persons has been directed toward the definition and measurement of the stressors that constitute the burden of those who become supporters of impaired family members or has focused on development and evaluation of intervention strategies. Although there is a growing body of research that deals with spouses of demented and chronically ill patients, there are relatively few studies that specifically examine the experience of men as caretakers. This chapter is designed to provide a review of relevant research with a focus on the experience of male spouse caregivers.

Caregiver Selection

Although the entire family system is generally impacted by the development of dementing illness of an elderly member, "family caregiving" is usually a euphemism for the efforts of one individual who assumes primary responsibility for the daily care and well-being of the elderly relative (Gilleard, 1984). Gilhooly (1984b) notes that once a single family member assumes caregiving responsibility, other members do not necessarily assist even if the burden increases and, in fact, are likely to provide even less care than they may have done previously.

It is the nature of family dynamics that the member who is most intimately related to the patient, usually a spouse if available, becomes primary caregiver. In the absence of a spouse, or if the spouse is unable, a child will assume the role (Johnson & Catalano, 1983). Shanas (1979) has identified a "principle of family substitution" by which siblings, nephews and nieces, or other relatives may assume the obligation if old people have no children. If no family members are available, friends or neighbors may provide some assistance to frail elderly persons (Stone, Cafferata, & Sangl, 1987).

Although impaired elderly people usually have at least one person who will provide some assistance, there is actually little depth in most family caregiving systems (Johnson & Catalano, 1983). Moreover, all caregiving is not equal. Spouses tend to provide the most comprehensive support over time and are the least likely to institutionalize the patient, even when experiencing considerable strain (Gilleard, 1984; Johnson, 1983; Johnson & Catalano, 1983; Lund, Pett, & Caserta, 1987; Morycz, 1985).

Adult children have realistic limitations on the amount of care they can deliver to impaired parents. Most have work and/or family responsibilities of their own. Children also, of course, are less likely to live with the parent. These factors may explain findings that children provide fewer personal services to parents and are more inclined to use formal services to obtain such help if it is needed. More distant relatives are even less likely to provide such care (Johnson, 1983; Johnson & Catalano, 1983). This means that persons with dementing illnesses, whose care needs generally increase over time, are extremely vulnerable if they do not have a spouse and have reached the point at which they require constant supervision and nursing care. If the spouse should become unable to continue caregiving, there is no guarantee that other family members will step in and provide the same level of support. Spouses appear to constitute the best chance for a demented elderly person to be cared for at home over the course of the illness.

Models of Caregiving

Research has suggested that caregivers may utilize a number of different models in organizing caregiving activities. Archbold (1982) identified two styles of parent caregiving by women: care providing and care managing. Care providers performed the physical labor of caretaking themselves. They tended to co-reside with the patient, have limited incomes, were not career oriented, and had limited social networks. Care managers had higher incomes, socially valued careers, and more facilitative social contacts. They were more able to organize and purchase services for their relative.

Gilleard (1984) suggests that spouses are seldom in a position to act as care managers. They are often retired and living on fixed incomes, which greatly hinders the ability to purchase assistance. In effect, spouses have more time than money to offer, and this influences the choice of becoming a care provider. Motenko (1988), however, found that men do in fact act as care managers in delegating and monitoring the informal care provided by other family members and the care provided by paid supporters. Horowitz (1985a) notes that a majority of caregivers utilize both direct care providing and care managing so that perhaps it is not a question of "either/or" but a melding of both styles for most individuals.

There is some evidence that the model chosen by caregivers differs according to gender. Women have generally had previous experience of caretaking, and may tend to utilize a model with which they are already familiar. Brody (1985) suggests that women often experience caregiving as a career, first to children, then to elderly parents or other relatives, and ultimately to a spouse. Miller (1987) found that wives compared phases of caregiving to child-rearing. Fitting, Rabins, Lucas and Eastham (1986) found that wives of demented husbands utilized a parent-infant model and thus regarded caregiving as a return to a former nurturing role.

However, a parent-child style is likely to collide with reality. There is a qualitative difference between the dependency of a child and that of an adult. Brody (1985) notes that there are different inner feelings accompanying the dependence of an elderly parent, and that caregivers have different reactions to behaviors, such as incontinence, that are developmental in a child but are symptoms of pathology in an adult. This may be equally true when the impaired person is a spouse upon whom one may have depended or had a relationship based upon shared responsibility and decision making.

In contrast, men who are caregivers are often retired and may look upon the caregiving "job" as a substitute for previous work roles (Fitting et al., 1986; Liptzin, 1984). Motenko (1988) also found that husbands assumed the job of caregiving in repayment for the past good job performance of their wives and took pride in doing it well.

The way in which caregiving is perceived as work may influence the styles of management used by husbands and wives. Fitting et al. (1986) found that male caregivers appeared to adopt a model derived from previous work settings related to organization, delegation, taking charge, and recognition of limitations. Husbands also were found to use an instrumental approach to daily problems (Zarit et al., 1986). They saw the illness as "mind problems" related to the disease and sometimes tried to act as teachers to impaired wives (Miller, 1987; Zarit, Orr, & Zarit, 1985).

From a different viewpoint, Miller (1987) proposed that control of another person is a central issue in caregiving and suggested that men and women perceive and manage issues of control in different ways. Men find it easier to assume authority over their impaired wives. This might be explained by the fact that caregiver husbands tend to be of the generation that expects men to exert authority in the home, so that dependency of the spouse is less of a qualitative change in the relationship. Women, on the other hand, have difficulty in assuming authority and making decisions that previously were the husband's prerogative, and sometimes go to great lengths to preserve their spouse's illusion of independence (Miller, 1987).

Spouses as Caregivers

Some studies indicate that spouse caregivers exhibit greater burden and strain when compared with adult children and others. George and Gwyther (1986) measured well-being in four dimensions: physical and mental health, social participation, and financial resources. Spouses were found to score lower in all areas. Cantor (1983) also focused on income and social isolation, as well as interpersonal relationships between caregiver and patient, and found spouses to be most negatively affected. In contrast, Morycz (1985) and Zarit et al. (1980) found no differences. Young

and Kahana (1989) found less caregiving strain among husbands and wives than among adult daughters and speculated that caregiving may be a normative expectation for older couples so that spouses perceive less distress, or that caring for a marital partner provides gratifications which offset the burden of caregiving. In the study by Zarit et al. (1986), husbands experienced less burden than wives, possibly because of greater tolerance of memory and behavior problems.

Research consistently shows that all caregivers experience restriction, sometimes very severely, on privacy, personal time, and participation in leisure activities (Cantor, 1983; Chenoweth & Spencer, 1986; George & Gwyther, 1986; Goldstein, Regnery, & Wellin, 1981; Gilhooly, 1984b). Spouses are more likely to be co-resident with the impaired person, and therefore are most vulnerable to social isolation as they become increasingly involved in meeting patient care needs (Gilhooly, 1984b).

There is some evidence that visits from family and friends may become less frequent either due to stigmatizing once the diagnosis is known or because people simply do not understand how to cope with the impaired person's behavior (Barnes, Raskind, Scott, & Murphy, 1981; Gilhooly, 1984b; Shifflett & Bliezner, 1988).

There may be other reasons for social isolation as well. Barnes et al. (1981) note that the sheer amount of

time and effort required for daily care often leaves caregivers with little opportunity or energy for social activities. However, Miller and Montgomery (1990) found that, although high levels of elder dependency and caregiving demands were characteristic of caregivers who reported social limitations, other factors such as caregiver gender and family relationship, subjective assessment of caregiving demands, education, and amount of back-up assistance available were more important influences on caregivers' perceptions of restrictions on social activities. Daughters, wives, and sons were found to report social limitations more often than husbands (Miller & Montgomery, 1990).

In the studies by Miller (1987) and Gilhooly (1984b), men were more likely to plan their routine so as to continue previous activities. To do this they were willing to leave their relative alone even when aware of potential hazards in doing so. Gilhooly (1984b) also found that men suffered less isolation because they received more help and hence had more social contacts. Women found their social lives restricted because they did not plan for regular activities, did not see leaving their husband alone as an acceptable alternative, and had difficulty in finding sitters or companions of whom the impaired spouse would approve.

Caregiver spouses may experience loss of social contacts for another reason as well. They may find that many friendships were based on being a couple. When their spouse is disabled, they no longer fit into former relationships. Some, who have quit working, discover that many of their social contacts were work-related and are no longer viable (Chenoweth & Spencer, 1986).

Miller (1987) found that both men and women were distressed that friends no longer saw them as a couple in quite the same way as before, but the way in which this problem was managed varied by gender. Women tried to reinforce the couple relationship by finding activities such as dancing in which the impaired husbands could still participate while men looked for individual activities.

Relationships with family, friends, and with the impaired spouse appear to have a significant impact on caregivers of both sexes. A number of studies show that emotional support from family and friends reduces the incidence of depression and influences caregiver perception of strain (Fengler & Goodrich, 1979; Scott et al., 1986; Zarit et al., 1980). Fitting et al. (1986) found that both husbands and wives are likely to receive emotional support from adult children and to have other confidants as well, although the circle of friends may be very small.

In general, the quality of family relationships prior to the impaired person's illness influences the

relationships afterward (Niederehe & Fruge', 1984). Families that have a history of conflict will likely experience discord over the care of their relative as well. The negative effects of a poor pre-morbid relationship between the caregiver and the patient have also been demonstrated (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984; Morris, Morris, & Britton, 1988), although other studies found that the quality of relationship was not significant to caregiver well-being (Gilhooly, 1984a).

The presence of dementia alters the marital relationship and often deprives spouse caregivers of companionship, support, and affection as well as sexual intimacy. Barusch (1988) found that relational problems such as missing the way the spouse was, resentfulness, arguments with the spouse, and failure of the impaired spouse to show appreciation were common and very difficult for caregivers to cope with.

Little research has been done on the sexual concerns experienced by caregiver spouses. Litz, Zeiss, and Davies (1990) suggest that caregivers do not report and seek help for sexual problems because they are reluctant to discuss sexuality or because they feel guilty and selfish in being concerned about their own sexual needs. Men may feel particularly distressed about initiating sexual contact with a spouse who might not be capable of consenting. Caregivers may also be concerned about frequent or unwanted sexual advances by the impaired spouse. Couples may have to alter sexual behaviors because the memory impaired spouse can no longer engage in the traditional and, for many couples, the acceptable way of having intercourse (Litz et al., 1990).

It might be expected that spousal caregivers, who are usually elderly and who tend to provide more care over a longer time than other family members, would most readily enlist formal support services. However, caregivers in general utilize relatively few formal supports despite frequent references in literature to the perceived need (Caserta, Lund, Wright, & Redburn, 1987; Gilhooly, 1984b; Snyder & Keefe, 1985). In the study by Snyder and Keefe (1985), more than 75% of caregivers used minimal social services (no more than one or two) even when a wide array of programs were available. Further, those who had been giving care longest were least likely to be receiving any support. Many caregivers indicate that they are not ready or don't need formal services (Caserta et al., 1987) but there may be other significant reasons.

When they do use formal supports, men and women exhibit different patterns. Husbands are likely to use homemaking assistance, while wives appear to regard housework as a duty that cannot be relinquished to others. Wives appear to be more interested in learning about the disease than are husbands. Women are more likely to participate in support groups and emotional counseling while men prefer activities

unrelated to caregiving (Miller, 1986; Snyder & Keefe, 1985).

Caregiving husbands have been found to receive more instrumental assistance from family members than have wives (Gilhooly, 1984b; Gilleard, 1984). Pruchno and Resch (1989) noted that women were more likely than men to be helping their spouses with tasks of daily living, and men more often received help from others with hands-on care. However, Kaye and Applegate (1990) found that men received relatively little assistance from family members, and many received none at all.

It is often suggested that the caregiving role is more difficult for men because it contradicts traditional stereotypes of male behavior. Men as a group, at least in the age cohort who are presently most likely to be spouse caregivers, are often not used to performing household and nursing tasks. They might be expected to feel less comfortable in the role and possibly more inclined to institutionalize their spouses. However, Vinick (1984), in a study of widowers who had been caretakers to disabled wives, found that most men accepted and successfully performed the necessary duties, often with great devotion. She also noted that most had a negative attitude toward remarriage and attributed this to their caregiving experience. Morycz (1985) found that the physical labor of

caregiving and age of the patient were more predictive of institutionalization than changes in role functions.

Male caregivers have been found to report less depression, demoralization, and hopelessness than women (Fitting et al., 1986). Gilhooly (1984a) also found that men reported higher morale and speculated that the males in her study were less emotionally involved in the patient's illness, less socially isolated, or simply less willing to admit distress. Davies, Priddy, and Tinklenberg (1986) suggest that men may be less willing to discuss negative feelings openly and may mask a significant degree of depression.

Women have generally been assumed to have more emotional involvement in caregiving than men, and this may explain findings in the study by Fitting et al. (1986), that men reported less deterioration in the marital relationship than did women, as well as the observation by Miller (1987) that wives perceived the husband's impairment in terms of its effect on the marital relationship. However, in the study by Pruchno and Resch (1989), husbands were found to be more invested in the relationship than were wives, and they more often expressed feelings that the care they were giving was due to their spouses.

The studies that have been done illustrate that men and women do appear to differ in the ways in which they perceive and manage the caregiving role. There may be differences in caregiving style, emotional involvement, perception of the disease, issues of control, and perceptions of change in the marital relationship.

The Process of Caregiving

Few studies have been done to examine the process by which caregivers enter and develop the caregiver role. Not surprisingly, research has mirrored the concerns of health care professionals and policy makers. The focus of interest on caregiving as a process has been primarily on the endpoint of family coping, the point at which families relinquish care to institutions. Factors that predict institutionalization (Lund et al., 1987; Morcyz, 1985) have been studied because of the perceived value to society and to the elderly of prolonging caregiving by families as much as possible.

Multiple definitions of caregivers and caregiving have made it difficult to conceptualize a single process (Barer & Johnson, 1990). Some researchers have characterized caregiving on the basis of the specific relationship between the care provider and care receiver, e.g., spouses (Zarit et al., 1986) or adult children (Horowitz, 1985b). Other studies have described the amount and kind of assistance (Mathews & Rosner, 1988; Stone et al., 1987) or patterns of care based on living arrangement (Soldo & Myllyluoma, 1983)

Small attention has been given to the beginning of the process, perhaps because the subtle onset of many cognitive

disorders of aging make it difficult to determine when caregiving actually begins. Willoughby and Keating (1991) identified a 5-stage process of taking on and relinquishing care that begins with a recognition of change in the elderly person and proceeds through phases of maintaining control and making decisions, transferring control of decision making to formal caregivers, and adjusting to the placement of the relative in an institution. The final phase of the process is described as "Moving On", building a life outside of caregiving.

Theoretical Perspective

Although both researchers and clinicians often refer to the "caregiver role", most research on caregiving has been problem oriented and has not included a specific theoretical perspective or framework. Since this study focused on the experience of men as they discovered and defined the role for themselves, and because of the usefulness of this perspective in describing the permutations of behavior within the context of relationships, role theory was used in the analysis and interpretation of data.

Role Theory

Role theory as developed by Turner (cited in Turner, 1982) postulates that interactions are dependent upon the identification and assignment of roles. As individuals interact, they attempt to make sense of each other's actions by grouping behavior into consistent and comprehensible units or roles. Roles tend to be complementary, e. g. husband-wife, parent-child and to regulate interactions between complements. Individuals vary in the extent to which a role is consistent with their conception of self and will attempt to inform others about their self-identity through cues and gestures. This view of role theory proposes that individuals define and alter their own roles instead of assuming culturally prescribed role definitions.

Applications of Role Theory to Caregiving

Role theory has previously been applied to family caregiving by researchers who studied caregiver burden and strain. Because of the enormous physical, financial, and emotional demands that may be placed upon family members who become primary supporters of dependent elderly relatives, the concept of role strain seems particularly apt. Role strain refers to the perceived or "felt" difficulty in meeting the demands of a given role (Goode, 1960).

Role conflict occurs when an individual has multiple roles with competing or mutually exclusive demands (Goldstein, Regnery, & Wellin, 1981). Conflict may describe the situation faced by an adult daughter who attempts to juggle the demands of marriage, children, and often a job as well as the care of an elderly parent.

Multiple roles do not always result in conflict or strain. Most people have multiple, often competing, roles and manage them more or less successfully. All roles do not make requirements at the same time, there may be mediating factors that act to reduce conflicting demands, or individuals are able to prioritize role demands (Goode, 1960). Strain results when role conflicts cannot be resolved. Caregiving, however, interjects a dimension of potential conflict because the needs of the dependent are always present, and caregivers may feel unable to meet but not free to defer or relinquish these obligations.

Role constriction or role fatigue result when a particular role, e. g. caregiving, supplants other roles and begins to force the caretaker into a tightly circumscribed set of activities (Goldstein et al., 1981). Care of a demented elderly person often evolves into a seemingly endless round of supervising, feeding, bathing, dressing, and changing soiled clothing that consumes the entire day and sometimes prevents sleep at night, leaving caregivers little time or energy for other activities (Gilhooly, 1984b).

The unending demands of caring for a severely impaired person can easily produce role overload, particularly if caregiving requirements are not merely physically but emotionally taxing as well. Pearlin (1983) notes that role overload in work situations is most likely to occur when workers have little sense of control. The workload related to caregiving is dictated by the exigencies of the illness

over which neither the patient nor the caregiver has control.

Role reversal is said to occur when other family members must assume role responsibilities of the impaired person (Teusink & Mahler, 1984; Barnes, et al., 1981). This concept is often applied when adult children begin to care for failing parents. The complex process that involves alterations in patterns of dependence, decision making, and leadership within the family is sometimes described as becoming a "parent to one's parent" (Teusink & Mahler, 1984). In a practical sense, caregivers find themselves taking on new responsibilities that may or may not be welcome. Wives may have to assume responsibility for business and financial affairs of which they were previously ignorant. Husbands may become household managers and learn to provide nursing care.

Pearlin, Mullan, Semple, and Skaff (1990) describe a number of caregiver role strains that act as secondary stressors and exert influence in addition to the stress created by the care needs of the impaired relative. Family conflicts about the kind and amount of care required by the ill person or over recognition of the caregiver's efforts by family members may create or exacerbate family grievances and result in strain. Caregivers who work frequently experience pressures related to conflicts between caregiving responsibilities and job requirements. Economic stresses

due to reductions in income or increased expenditures related to care of the relative and restrictions of social activities are also identified as role strains (Pearlin et al., 1990).

Some individuals may become caregivers reluctantly from a sense of obligation or because there is no one else. Role captivity is a source of strain when caregivers are unwilling (Pearlin et al., 1990).

Although concepts derived from role theory have been used extensively to delineate the dimensions of caregiver strain and burden, little attempt has been made to use a theoretical framework to examine the process by which family members become caregivers. In this study of older men caring for cognitively impaired wives, the role theory perspective was used to examine the way in which husbands restructured their roles and relationships in order to cope with the enormous changes in their lives.

CHAPTER 3

METHODOLOGY

Rationale for Qualitative Design

Many excellent studies on caregiving have been done during the past two decades. Most research has used quantitative techniques such as survey and quasi-experimental designs. The primary purpose of such studies was to enumerate and explicate the tasks and burdens faced by caregivers and to develop and evaluate supportive programs to assist caregivers with those problems. Research by Cantor (1983), Gilhooly (1984b), Sanford (1975), Zarit et al. (1980), Zarit et al. (1985), and numerous others has nicely documented these aspects of caregiving.

Some research, such as the recent study of dementia caregivers by Pearlin et al. (1990), has used a combination of qualitative and quantitative methodologies. However, relatively few studies have used qualitative methods as primary research strategies (Motenko, 1988; Willoughby & Keating, 1991; Wilson, 1988). The relatively recent recognition that caregivers consist of several subgroups, each with their own phenomenological experience, demonstrates that there is more to learn about the lives of caregivers and the ways in which they perceive the caregiver role. It is in this realm of caregiving that qualitative methods can be most useful.

Qualitative methodology produces depth and richness in research findings that results in "thick description" that permits detailed analysis and is useful in the conceptualization of problems in terms of processes (Marshall & Rossman, 1989).

Qualitative studies are undertaken in natural settings where people actually live. Such studies are concerned with how individuals themselves define and assign meaning to their experiences. Therefore, researchers can ask questions that cannot be adequately answered in more structured experimental settings.

Grounded Theory

"The grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon" (Strauss & Corbin, 1990, p.24). Grounded theory was chosen as the analytic approach for this study for several reasons. First, this is an exploratory and descriptive study. The purpose of the research was to examine the experience of male spouse caregivers as they perceived it and to discover the meaning of that experience for them. Men caregivers are a largely unstudied subgroup of the caregiver population. There has been considerable stereotypic and mythologic thinking about males as caretakers, but little research-based theory development has been done.

Grounded theory is a useful method in areas in which

there has been little previous research and few relevant variables have been identified (Chenitz & Swanson, 1986). Grounded theory permits the asking of research questions that are flexible enough to allow full exploration of the phenomenon (Strauss & Corbin, 1990).

Another reason for the selection of grounded theory is that this method permits intensive data analysis when in-depth interviews are obtained from relatively small samples. As a result grounded theory methodology is particularly useful for generating theory when little is known about the phenomenon or process being studied.

The Process of Grounded Theory

The essence of grounded theory lies in the process of constantly questioning, comparing, and coding of data in order to identify phenomena, detect relationships, and demonstrate processes. Three types of coding are used: Open coding, axial coding, and selective coding.

The process of analysis begins with open coding during which the data is closely examined and broken down. Key concepts are identified by the process of comparing incidents and examining the data so that they can be grouped together to form a higher, more abstract level of conceptualization. The categories which emerge from this process are then developed in terms of their characteristics or properties and are dimensionalized or located along a continuum (Strauss & Corbin, 1990).

Open coding breaks down data so as to identify its core categories. The second type of coding, axial coding, is concerned with the reassembly of data in new ways by developing each category in terms of conditions that cause it, the context within which it occurs, the strategies by which it is managed, and the consequences that result (Strauss & Corbin, 1990).

Selective coding refers to the process of selecting the core category and relating it to other categories. The core category is the central phenomenon of the analytic story and the one to which all other categories are systematically linked (Strauss & Corbin, 1990). It is from the core category and its relationships that theory is developed.

Reliability and Validity

Reliability and validity are managed differently in qualitative research than in quantitative studies. Reliability or consistency in quantitative research depends upon the accuracy of the measuring instrument. The key to reliability is the ability to replicate the study (Chenitz & Swanson, 1986). That is, if the same or another researcher were to repeat the study using the same instrument under the same conditions, would they obtain the same results?

Lincoln and Guba (1985) submit the criterion of auditability as the measure of consistency in qualitative research. A study is auditable when a second researcher can clearly understand how analytic decisions were made. Given

the same theoretical perspective and following the same rules of data collection and analysis, another researcher should be able to develop the same theoretical explanation (Strauss & Corbin, 1990). By keeping field notes and all other data available, the researcher can answer any questions about findings and make them available to others who might wish to replicate the study (Marshall & Rossman, 1989). In order to maintain an audit trail for this study, interviews were tape-recorded and transcribed. Theoretical memos were also written throughout the process of analysis. Internal validity is concerned with how well an instrument measures what it is supposed to measure so that findings are free of artifacts related to characteristics of the subjects, the instrument, or the process of data collection and analysis (Sandelowski, 1986). In qualitative research the term "credibility" has been suggested as the measure of the "truth value" of the study (Lincoln & Guba, 1985). A study is credible if the phenomenon is so well described that it is recognizable both by individuals who have had the experience and those who have merely read the study (Marshall & Rossman, 1989; Sandelowski, 1986).

External validity refers to the generalizabilty of findings beyond the sample being studied. The usual method of achieving generalizability in quantitative design is to obtain randomized samples of predetermined sizes and to further randomly assign subjects to experimental and control

groups (Sandelowski, 1986). Qualitative research typically involves small nonrandom samples and is frequently criticized as nongeneralizable (Marshall & Rossman, 1989; Sandelowski, 1986). Borman, LeCompte, and Goetz (1986) note that, although qualitative studies are thought to be nonrepresentative, in fact many of the phenomena that are studied do have similarities to other situations. If the research is carefully done, conclusions can be applied in other contexts.

Patton (1990) suggests that generalization can rob a study of context and offers the alternate concept of extrapolation or speculation about the applicability of findings to similar situations. Brink (1989) states that since qualitative studies seek to describe and explain phenomena, generalizability is not the goal. Other researchers prefer to discuss translatability and comparability rather than external validity. These concepts depend upon very careful definition of methods, categories, and characteristics of phenomena so that comparisons with similar populations and settings can be made (Borman et al., 1986).

A number of strategies are available to qualitative researchers that will enhance the transferability of a study to other settings. Triangulation, or the use of multiple approaches to data collection, is useful for some studies (Borman et al., 1986; Marshall & Rossman, 1989). Constant

comparisons and the search for negative cases help to ensure that categories are saturated and strengthen the validity of grounded theory.

Research Design

This research was designed as a nonexperimental descriptive study using a grounded theory approach to data analysis. Data was collected by means of in-depth semi-structured interviews.

Sample Selection

Subjects for this study were male spouse caregivers of cognitively impaired wives. Men were selected if they spoke English, had cared for their spouses at home for at least one year prior to the interview, defined themselves as primary caregivers, and if they agreed to participate in the study after receiving an explanation of the research and its purpose. In order to increase researcher knowledge about male caregivers, 2 caregiver sons and 1 husband whose wife had been disabled but not cognitively impaired were interviewed. Information obtained from these individuals was used for comparative purposes and was not included in the analysis of findings.

A variety of sources were used to recruit potential subjects for the study. Facilitators of caregiver support groups in the area were asked to announce the study to their participants and obtain the names of any men who were interested. Senior Access, a nonprofit organization that

provides home care, day care and supportive services to frail elderly and disabled persons and their families, was contacted and agreed to screen their clients for potential subjects. A request for subjects was also placed in the newsletter of a local chapter of the ADRDA (Alzheimer's Disease and Related Disorders Association).

Potential subjects were first contacted by letter to inquire if they were willing to consider being in the study. Those who did not desire further contact returned a postcard. Subjects who did not return the postcard were then telephoned and scheduled for an interview. Fifteen men agreed to participate and were interviewed. Two men refused after initial contact, and one subject was dropped from the study prior to interview because of the sudden death of his spouse.

Human Subjects Approval

Approval to conduct the study was obtained from the Committee on Human Research of the University of California, San Francisco, and from the Board of Directors of Senior Access, Marin County, California.

Consent From Subjects

All subjects signed a consent form after an explanation of the study was given, and all subjects gave permission for tape-recording of the interviews. Subjects were given a copy of the consent form (Appendix A) and the Human Subjects Bill of Rights. Interviews were conducted in the homes of

subjects unless they preferred otherwise. In that case, another private place of their choosing was used.

Confidentiality

Confidentiality of data was maintained by keeping names of subjects in a locked file separate from all other data. All tape-recordings and transcriptions of interviews were coded by number.

Data Collection

Data was collected by means of in-depth interviews. Each interview lasted 2-3 hours.

The interview guide consisted of open-ended questions designed to allow subjects maximum freedom to describe their experience in their own words (Appendix B). Interview probes were used if subjects had difficulty understanding any open-ended questions or drifted from the topic. Subjects were asked questions relating to how their lives might have changed since becoming a caregiver, how their relationships with their spouse, friends and family might have changed, and how they managed caregiving. They were also asked if they perceived that anything might be different or unique in the experience of men caregivers. As categories emerged from the data, questions were asked around these categories. The researcher frequently requested subjects to validate her understanding of their responses by saying, "So you felt that this was happening" or "From what you said, I understand you to mean", etc.

This technique was found to provoke additional and often more detailed information from subjects.

Sample Characteristics

The sample consisted of 15 white males who were caregivers of cognitively impaired wives. Basic demographic data was obtained from all subjects prior to the interview (Table 1).

Caregiver husbands ranged in age from 67-88 with a mean age of 76.9. Since the caregiving experience is inextricably bound to marital and family relationships, the number of years married was also considered to be relevant. Length of marriages ranged from 9-58 years. Because of the wide range, the mean of 42.9 years was considered to be less informative than the fact that 13 of the fifteen couples had been married for more than 20 years, and 9 of the couples had been married 50 years or more.

Educational experiences of subjects varied widely. Two men did not graduate from high school, 2 were high school graduates, 4 had some college, 3 were college graduates, and 4 had graduate degrees.

Subjects were asked to indicate their monthly family income as a guide to determining their available financial resources for caregiving. Several men were reluctant or unable to do so precisely, and some were supplementing their income with the proceeds from investments or savings as needed so that only a very rough estimate could be obtained.

Seven men, nearly half the sample, reported incomes of $3000/month or more.

Subjects were also asked to self-rate their health. A majority rated their health as excellent or good, and none stated that they were in poor health.

Table 1

Demographic Information

N=15

Age of Caregiver

67-75	5
76-85	9
86+	1
Mean	76.9

Years Married

Range	9-58
Mean	42.9
Married 20 Years or More	13
Married 50 Years or More	9

Education of Caregiver

Didn't Graduate High School	2
High School Graduate	2
1-3 Years College	4
College Graduate	3
Graduate Degree	4

Income/Month

$1200-1500	1
$1501-2000	5
$2001-2500	2
$3000 & Up	7

Self-Reported Health

Excellent	4
Good	6
Fair	5
Poor	0

Living Situation

Spouse Living at Home	8
Spouse in Nursing Home	2
Spouse Deceased	5

Data Analysis

In accordance with the grounded theory method, open coding began with data collection. The first interviews were coded and compared. In order to identify and describe the maximum number of variables, subjects for succeeding interviews were chosen to ensure the widest possible diversity of experiences. Subjects were selected who varied in whether or not they had children, in the type and amount of community and in-home assistance they used, and whether they used support groups. Subjects were also selected to have a range of educational backgrounds and income levels and therefore a variety of resources potentially available to them. Two men had previous caregiving experience, and 2 men had previous marriages.

Characteristics of the wives were also varied. Ten spouses suffered from probable Alzheimer's Disease, 1 had Huntington's Disease, 1 had Post Encephalitic Dementia, and 3 had no formal diagnosis. Because the full range of caregiving experience was sought in this study, the sample included 8 men whose wives were living at home, 2 whose wives were in nursing homes, and 5 men whose spouses were deceased within a period of 6 months to 3 years prior to the study.

As data collection proceeded, axial coding was done to identify the relationships between the emerging categories (Strauss & Corbin, 1990). During analysis, the developing

theory was discussed with other researchers who were familiar with the grounded theory method, and who reviewed data obtained from the interviews. Memos were written throughout the processes of coding and analysis. These memos and were later used to guide development of the substantive theory of role embeddedness.

CHAPTER 4

ROLE EMBEDDEDNESS

Men in this study who became caregivers of their cognitively impaired spouses experienced a profound alteration of their lives. They became embedded in a role that preempted their identity as husbands and confronted them with unfamiliar issues of intimacy, dependency, and loss. Caretaking involved activities that were, in most cases, outside the realm of previous experience and for which traditional expectations of male behavior had not prepared them.

This chapter will discuss the properties of role embeddedness and describe the process by which these men entered and maintained the caregiver role.

Definition of Role Embeddedness

Kaye and Applegate (1990) described male caregivers as "deeply embedded" in a role that is normally regarded as belonging to women. For the husbands in this study, being embedded in the caregiving role generally meant that daily activities were constricted and shaped by the care requirements of their impaired wives. Caregiving became, for most husbands, a central experience that dominated their lives and impacted relationships with their wives, friends, and family. Not only was daily life affected by the illness of their spouses, but most husbands were forced to surrender plans that they had made for the future. Once immersed in

caregiving, husbands found it very difficult to contemplate relinquishing the role. The concept of role embeddedness describes the preemptive nature of caregiving as an evolving process that eventually takes precedence over other dimensions of caregivers' lives.

Reciprocity and Solidarity

Husbands interviewed for this study chose to become caregivers for several reasons. They reported that they loved their wives and found mutuality in the marital relationship. Love and mutuality, developed over many years of marriage, allowed them to find satisfaction in caring for their spouses. One man described his feelings in this way:

> [There is] very deep satisfaction. You're caring for someone you love very deeply and have shared so much with all over the world for 37 years.

These men also cared for their wives as an expression of the social norms of reciprocity and solidarity. These norms are used by social scientists to explain the give and take of benefits and rewards in social relationships.

Husbands in this study cared for their wives in repayment for a good marriage and past support and because they were certain that if the situation were reversed, they could have counted on the same care from her. One man recounted that his wife had spent many days nursing him through malaria which he had acquired in World War II. Others expressed similar feelings:

Paul: It has to be done. What the heck. You live with a person all these years...she'd do the same for me.

Fred: If I was in the same condition she was, she'd be doing the same for me.

Social exchange theory postulates that the general principle governing human interactions is the norm of reciprocity. That is, in order for a relationship to develop and be maintained, both parties must find the interaction to be profitable. The norm of reciprocity helps to ensure that individuals who receive benefits from a relationship return rewards, preferably of equal value, either directly or at a later time. In general, the norm of reciprocity mandates that we should help those who have helped us (George, 1986).

Reciprocity, however, does not explain certain interactions in which one party to an exchange receives far more in benefits than they are able to repay, thus creating an unbalanced relationship. The norm of solidarity involves a commitment to a relationship without consideration of repayment. Solidarity normally applies to only a few relationships such as the close and complex ties that occur within the family (George, 1986). In this society, it is generally expected that if a family member requires assistance, others within the family will provide that

support if possible and will continue for a prolonged period if needed.

Husbands in this study continued caregiving, despite the many problems they encountered, until they could no longer manage their spouses' care requirements. They did so because they perceived that their wives wanted and needed to remain at home. In order to meet these needs, husbands shouldered enormous physical, emotional, and financial burdens.

> Henry: One thing I'm sure of. As long as she recognizes me and reacts toward me as she's doing, and as long as she appreciates her home...I couldn't begin to think of putting her away in a nursing home.
>
> John: We kind of made a vow...and I kept my word, I kept her at home.

Caregivers in the study used a number of strategies such as fatalism, religion, and acceptance of the spouse as she had become in order to maintain solidarity and continue caregiving. One man said:

> I always felt that this is it. This is what God wished on us, planned for us, and we do the best we can.

Another husband, who had cared for his wife at home until she died, explained that he loved and missed her despite the

changes in personality and cognition that resulted from her illness:

> That's what I miss [taking care of her the way she became] more than the parties and the good times we had, because anybody can do that. I think that is what I miss really, taking care of her. And I miss her like all get-out.

Entering the Role

For most of the men in the study, the recognition that their lives were being irrevocably altered emerged slowly over a period of months or years. The majority of their spouses suffered from Alzheimer's Disease, which typically has an insidious onset. The earliest signs of small memory lapses and decrements in function were difficult to recognize and were often misinterpreted.

Marked behavioral changes in the wives gradually became apparent. One wife began to grow sloppy in her cooking, leaving out seasonings, etc. Another began to get lost while driving. A third spouse could not learn to play golf or use a microwave. She also began to lose her conversational repertoire and repeat the same stories over and over.

Although the husbands eventually noticed significant behavioral deficits, they often attempted to normalize symptoms as due to aging or attributed them to other more readily comprehensible problems. One husband thought that

his wife's growing inability to function socially was the result of her hearing impairment. Another man, whose wife began to drink heavily, suspected she was becoming alcoholic until he realized that she no longer understood the difference between alcohol and nonalcoholic drinks. Other husbands blamed mental illness, depression, or stubbornness for the changes in their wives. In some cases the men stated that they simply did not question substantive changes in behavior. Several husbands reported that wives who previously had managed the family finances and business affairs suddenly relinquished the checkbook and refused to continue. One man described an incident with his wife of more than 40 years:

> I came home and she said to me at dinner that night, "You're going to have to take over the checkbook." I said, "Why?" She said, "Well I think you better take it over now." She was very evasive. I didn't suspect too much....

For the husbands who were interviewed, recognition of the change in their roles occurred when they reached a point at which they could no longer normalize changes in the behavior of their wives, when they realized that corresponding changes had taken place in their own behavior, or when they were confronted with a specific medical explanation of the change their spouses.

Turning Points

In order for the husbands in the study to begin to think of themselves as caregivers, they had to accept that something was wrong in the behavior of their wives. Three conditions which illustrated the changes in their lives were commonly described: dramatic changes in the behavior of their spouses, recognition of the dependency of their spouses, and medical confirmation of an illness that the husbands perceived as requiring a caregiver.

Dramatic Change in Spouse

When asked questions about when they realized that they had become caregivers, some husbands unhesitatingly described incidents that had dramatized the change in their spouses. Not surprisingly among this sample of older men, the turning point often came when they attempted one of the great American traditions of retirement. For many people retirement is the time to travel, to do the things you never had time or opportunity to do during your working life. These men discovered that they had waited too long. One man described his intent to build a retirement home near a lake where children and grandchildren could gather and recounted how he and his spouse had made many plans:

> We were going to do a lot of traveling. We didn't do anything while I was working. And that's a foolish thing to do. Day by day and don't wait.

Many subjects reported that their wives were not only unable to cope with the changes in routine and environment necessitated by retirement plans, but they were often actively resistant so that the husbands were unable to indulge their interests. One man said that he had greatly looked forward to a trip to a distant city to complete some genealogical research. His wife had agreed to this, but when they arrived, she lost interest in the project and could not tolerate being away from home.

Another subject described a nightmarish journey across country. He had purchased a trailer with which he planned to take a leisurely journey to visit relatives. His wife became increasingly agitated, began running away, and on one occasion pulled the keys out of the ignition while they were on the road. He was forced to leave the trailer and fly back home with her. " That," he said, "is when she really turned sour."

For the men in the study, "turning sour" was manifested in a variety of ways. One man stated that his wife had always been difficult, but she became paranoid and aggressive which resulted in a number of contacts with the police. Two husbands reported that significant changes in their wives' cognition occurred following major surgery. One man reported that his wife, who was showing signs of cognitive changes, lost her job. Another spouse became seriously ill with encephalitis. When she miraculously

recovered, it was apparent that she had suffered brain damage with severe memory loss and functional deficits.

Recognition of dependency

Some subjects had difficulty in identifying the point at which they realized they were now caring for a dependent person. They simply took on more and more of the functions that their wives had previously performed. They began to do cooking, housekeeping, and manage family finances. Some men began to recognize the change in their role when they could no longer manage to care for their wives without help. One man explained:

> I'm not sure when I started to take care of her. I didn't start to think of myself that way [as a caregiver] until I hired the two ladies, and I couldn't do it myself. That's when I started to wonder about it.

Medical Diagnosis

Some husbands in the study began to define themselves as caregivers when their spouses were diagnosed with an illness which they perceived as requiring a caretaker. One man stated that he had cared for his wife long before she was finally diagnosed but did not think of himself as a caregiver until he learned that she had Alzheimer's Disease. Another husband, who had just made the decision to place his wife in a nursing home, reported that he had not known he was a caregiver until six months earlier. Although he had

cared for his spouse as she declined over a period of nearly five years, he felt inadequate and guilty because he had been a "caregiver" for only a short time before having to relinquish her care to others:

> See the diagnosis was only a few months ago, and I felt like as a caregiver, to be worthy of the name, I should have been in this longer. In other words...probably she's had some variety of this for some years, but it was only pinned down in the last few months. So that in a sense I was only taking care of her in the last few months.

The turning points that subjects described did not, for most of the men, mark the beginning of caregiving. Only 1 of the 15 husbands appeared to have defined himself as a caregiver suddenly and definitively when his wife became impaired following an acute illness. Most men in the study found it difficult to identify the exact point at which they became caregivers because of the gradual and subtle onset of their wives' dependency.

The events that emerged as turning points appeared to be significant to the husbands in several ways. These were often dramatic and unforgettable experiences which illustrated to the men that their lives were not going to be what they had planned. Turning points allowed the men to construct a beginning for the change in their role and begin to think of themselves as caregivers. For some subjects,

turning points provided a place from which to launch the story of their experience. As they described their caregiving to the interviewer, they first related these incidents and then moved back and forth along the continuum of their experience to fill in details.

Becoming Embedded in the Role

As they recognized the growing dependency of their wives, husbands in this study began to develop a sense of themselves as responsible for the care, well-being, and quality of life of their spouses that firmly embedded them in the role of caretaker.

Reliance on Self

The husbands interviewed for this study were forced to become self reliant as caregivers. In most cases subjects described themselves as solely responsible for the care of their spouses. They received relatively little assistance either from family members, notably their children, or from other informal or paid support services. These men regarded themselves as primary care providers of their wives and also as decision makers for issues of great importance such as selection of paid caretakers or placement of the spouse in a nursing home.

Limited Family Support

Children are the obvious source of support and assistance for spouses who are caregivers. Eighty percent of the men in this study had children, and most had two or

three. However, only 17% reported receiving significant support in the form of shared caregiving or financial assistance from their children. The men often described their children as not wanting to be involved in caregiving and as disengaged from themselves and their spouse.

None of the men interviewed reported that he expected his children to alter their lives in order to help care for their disabled mother. None of the men believed that his children would become caregivers even if he should die or become ill and unable to care for his wife. When asked what would happen if he could no longer care for his spouse, the caregiver invariably said that he would have to place her in a nursing home. Those men who were financially able to do so had made plans in the form of trusts, investments, or allocation of pension funds to provide for this eventuality. Those who had already reached the limits of coping and had placed their wives or whose wives had died also indicated that they had not considered asking children to take over her care.

The men gave a variety of reasons for the failure of their children to participate. Children were often geographically unavailable. In some cases, children were unable to help or were themselves in need of assistance. Some subjects did not want to burden their children, and sometimes the children were unwilling to become involved.

Many subjects reported that their children had

established families and careers in distant cities and were not available to provide assistance on a regular basis. These men accepted that the first priority of an adult child is to his or her own family.

For the men in this group, children often were simply unable to provide much assistance. Daughters and daughters-in-law, traditionally regarded as mainstays of family caregiving, often had children to care for or were working out of necessity to support themselves and their families.

While struggling to cope with the burden of their wives' illness, 20% of the men in the study had been providing some support to their children. One man, who was draining his savings to pay nursing home fees for his wife, was also providing financial assistance to his daughter. Other subjects related that children had been or were still living at home, some because they had not yet moved out, and others because of illness or other problems.

Some caregivers wished to protect their children from the conflicts and problems created by a situation with which the husband was already familiar. One man whose mother-in-law had lived in his home described his reasoning:

> It's one thing to have one family put out, why have two or three. It doesn't necessarily mean they don't love you.... With [wife's mother] I sometimes resented it. The thing I resented was [the family] had four kids...[his wife and one

> sister did all the care. The other siblings refused to help. He did not want to create that kind of situation for his own children].

In some cases, particularly when there were already problems in the relationships between the children and parents, strain was exacerbated because the children could not accept or cope with the illness of their mother. One man related the situation with his two daughters:

> They are relatively little companionship to me or their mother. And certainly not caregivers. They don't want any part of caregiving. But I have discussed with them questions about institutionalizing [wife]. And I've also discussed with them about what if something happens to me. The first response is, "Well, we would want to take care of mother." I said, "Are you kidding?" They know that's not realistic. And I said, "Well, you'd have to put her into a convalescent hospital. You'd be able to manage that."

Another husband reported that his daughter was angry because her mother was ill and cognitively "lost" to her and simply refused to participate in her mother's care. A man whose wife was severely impaired with Alzheimer's Disease related that his son, a medical doctor, rarely visited his

mother because he didn't think anything could be done for her.

Noninvolvement by children meant not only that caregiver husbands did not receive instrumental support for their caretaking endeavors, but they had to rely on themselves when making significant decisions. Husbands whose children were not involved had to make the painful decision about nursing home placement by themselves. One man said of his daughter:

> She'll be the last to know [When I decide to put my wife in a nursing home]. It'll be an accomplished fact when she hears. I have a sense that she probably won't like it and won't like it that I didn't discuss it with her, but I haven't been able to discuss anything about this with her because she didn't want to know about it. So its her own fault.

Subjects whose children did choose to be involved reported that they participated in limited ways. Children provided moral support and "checks" by telephone to ensure that caregivers were managing all right. Sons and daughters who lived at a distance would sometimes visit and offer respite by taking over household and caretaking duties for a brief period. Children who lived nearby would occasionally take their mother for an outing or stay with her for a short

period so that the husband could have some time for himself. One man reported regular financial assistance as well.

Support and approval from their children was very important for those men who decided to place their wives in nursing homes. Several men stated that their daughters had helped them to evaluate and select an acceptable facility. One of the men who had no children felt keenly the burden of being solely responsible:

> I was the one that made all the decisions. In a way it's my own fault. If I'd just had some children. That's where children are helpful.

Attempts to involve unwilling children in caregiving were unsuccessful and tended to create increased tension. One man described his daughter's response to his efforts:

> Last time she [daughter] was over my wife had to be walked to the back.... My daughter, I invited her to help walk her back, one on each side. And she didn't want to. She decided to go home. So I was a little miffed at that. I thought she could have joined a little bit in this.

Younger caregivers might be able to negotiate some support from siblings or other family members who are age peers. However, for the elderly husbands in the study, this was rarely a viable option. Siblings and in-laws were generally old themselves and often had health problems or were already caring for a disabled person. Many friends and

relatives had died so that the caregiver's potential support network was very limited. One husband graphically illustrated this as he enumerated one after another of his friends and family who were dealing with problems of their own and could not help him.

For the husbands who were interviewed, efforts to gain recognition and understanding of their problems sometimes met with denial from family members who could not accept the diagnosis. One man who had his wife evaluated and diagnosed with Alzheimer's Disease attempted to no avail to explain the significance of her symptoms and enlist the support of his brother-in-law:

> Her brother [who lived in a distant city] used to come up, and he'd say, "I don't think she's got Alzheimer's."

Limited Support From Health Professionals

Physicians are likely to be the initial contact for caregivers who are aware that something is wrong and are seeking an explanation of the changes in their relatives. However, most subjects in this study reported receiving little assistance from their physicians. In a number of cases, they had difficulty in getting a diagnosis for their spouses, and felt that physicians were sometimes tactless in informing them when the diagnosis was made. Several women were being treated for other medical, surgical or psychiatric conditions, and those physicians seemed

unwilling to deal with symptoms of dementia. Husbands often had to be assertive and persistent in reaching a physician who would make a diagnosis. One man reported his experience with a psychiatrist who was treating his wife:

> I sat in on the sessions with her. It was I who finally broke the logjam. I said, "Dr..., I don't think we're getting anywhere. I have a feeling that she needs another brain scan." He said, "I'm beginning to think you're right." I don't know why he didn't volunteer that. [They were then referred to a neurologist.] That was the factor that broke it open and led to a diagnosis very quickly.

Although most men in the study said that a diagnosis of their wives was important to them, they did not necessarily understand the implications. For some husbands, even a diagnosis did not prepare them for the enormity of the changes that would occur as their wives became increasingly disabled:

> I said, "[wife], don't worry about it. If you lose your memory, I'm here to help you." I didn't think it was going to be anything like it was.

In some cases, physicians failed to adequately prepare caregivers for problems that they would encounter and did not take steps to ensure that they understood the nature of the illness. One man said:

> You know, you would think her doctor would have said, "Well, Fred, I realize you're going have to go through quite a bit and everything, but I'd suggest you contact your lawyer first thing and get a power of attorney." I didn't realize this disease was going to progress that fast.

One husband, whose wife had been involved in several public episodes of aggressive behavior, said that he attempted to explain to her physicians that something was wrong, and she needed to be "straightened out." His wife, meanwhile, had made numerous complaints to her doctors about him and apparently was believed. The husband related with exasperation that he was told he was the "sick" one.

In general, the husbands interviewed for this study did not see physicians as helpful in managing the day-to-day problems associated with care of their wives. "What can he do," said one man, "Can he tell me how to put on a Depends?" Nurses and social workers were considered to be more helpful than physicians in offering advice and information, emotional support, and assistance in decision making. The men also used support groups and self-help publications as sources of information and assistance.

Limited Community Support Services

Husbands in the study encountered two major barriers to use of formal community support services: unavailability of suitable services and high cost.

Most of the men attempted to use adult day care centers as a source of respite. However, they found that these facilities were not always prepared to manage common symptoms and medical problems of cognitively impaired patients such as incontinence, agitation, and resistant or aggressive behaviors. One man stated that, when his wife began to have seizures, he had to withdraw her from a day care program because of the provider's concern about liability. Several caregivers reported that they had attempted to use day care but the staff was unable to manage their spouses' behavior. When professional caregivers could not manage the wives, they simply turned the responsibility back to the husbands.

Caregivers in the study reported other problems with use of respite programs as well. Transportation was not always available. Although most of the community respite programs that were used by subjects did provide transportation for participants, some of the men lived too far away and could not use the service. By the time they had dressed and fed their wives, driven them to the day care facility, and then returned in the afternoon to take them home, they actually gained little relief from use of the program. One man who attempted to use community transportation reported that the service would not accept his wife because she refused to wear a seat belt. He had to

transport her himself until he was finally able to devise a method of securing the belt so she could not unfasten it.

A number of husbands used paid home attendants. Most reported that it was difficult to find individuals who could manage their wives successfully, and the majority would have liked more attendant care than they were able to obtain.

A major problem in use of paid respite care for most subjects was cost. The majority of men in this study were reasonably affluent and not eligible for Medicaid or other financial assistance with caregiving expenses. Seven of the husbands, nearly half the sample, had incomes in excess of $3000/month. However, they were often using income from savings and investments in order to meet the costs of care for their wives. The men who did not have extensive assets to draw upon were very limited in the amount of services they could purchase.

One caregiver reported that the cost of care for his spouse, including hidden costs such as extra water and electricity for the increased amount of laundry required because his wife was incontinent, was $2000/month. This man acknowledged that he could not afford to pay for more care if it should become necessary. Another husband who sought respite care described being caught in a "Catch-22" situation. On an hourly basis, a day care program was less expensive than the cost of a home attendant. However, the day care center was reluctant to accept his wife unless he

sent her regularly several days each week, and this cost more than he could afford. His solution was to hire an attendant only when he had to do so. A man who had to place his wife in a nursing home on Medicaid summed up concisely: "You can't be poor and have Alzheimer's Disease."

Most caregivers in the study did express satisfaction with the formal support services they were using. If they were not satisfied or had a bad experience, they simply stopped using those services, and usually indicated that they were reluctant to try again. Husbands were very much aware that the ultimate responsibility was theirs, and they reinforced their sense of being responsible by setting high standards for the care that their wives received from others. They were proud of their own caregiving and were reluctant to relinquish care when they could not ensure that their standards would be met.

Caregivers in the study discovered that acute care hospitals also had difficulty in providing care to dementia patients and would return responsibility to them as quickly as possible. Two men related that their wives, who were quite demented, were sent home early from the hospital following major surgery. One man said that he was requested by the nurse to take her home as soon as possible because "she's too much for us."

Aspects of the Caregiver Role

Most of the men who were interviewed reported that, in the early stages of illness, their wives retained the ability to care for personal needs, socialize to some degree, and perform some household tasks. However, as the women deteriorated, the husbands gradually became more embedded within the caregiver role and were increasingly involved in both providing and managing care.

Providing Care

As care providers, the men found themselves taking on responsibility for meeting basic physical needs of their spouses. Husbands learned to bathe, dress, and toilet their wives. Aside from issues of privacy and intimacy which arose from such tasks, there were technical aspects of nursing care that were unfamiliar to most of the men and often had to be learned by trial and error. One husband explained:

> I had to learn to fit her in her brassiere. This is something you wouldn't even think of, but a man doesn't put a brassiere on a woman. But I found that I could reach and kind of lift her up from behind. I do a lot of things from behind.

Much of the care that the men gave required extraordinary patience and persistence because their wives were often either actively resistant or unresponsive. This in turn led to frustration and exhaustion. One man

described the difficulty he had in undressing his wife because she would grab and hold on to her clothing as he tried to remove it:

> The other thing is grabbing.... Sometimes there'll be ten or eleven grabbings before I get a blouse off her. By that time I'm frazzled. It just drives you up the wall when you're tired too.... She thinks she's holding herself up. I have to force her hand up onto something to hold onto that's meaningful.

The husbands were forced to utilize ingenuity in devising solutions to problems that fit their particular circumstances. One subject described how he experimented with various sizes of disposable undergarments and then found a special way of making the bed with a rubber sheet so that his wife would stay dry at night.

For some men in the study, care providing continued even after placement of their wives in a nursing home. If they felt that their spouse needed care that was not being given, they took matters into their own hands:

> I go out to see her every other day. I walk her. They don't walk her; she's in a wheelchair.

Caregivers in the study also considered themselves responsible for the quality of life their spouses enjoyed:

> You do anything to make the quality of life as good as you can. Just a moment of laughter, a

> moment of savoring.... She loves yogurt; I get her frozen yogurt all the time, anything that makes her have a moment of happiness.

Husbands recognized the vulnerability of their spouses and began to protect them from the consequences of physical frailty and impaired judgement. The men frequently insisted that their spouses could not be left alone, and were constantly watchful to prevent household accidents.

> Tom: Sometimes she'll grab her coffee.... I have to be very careful with coffee or she'll scald herself.
>
> Dan: I can't forgive myself for a terrible accident about a week ago. [His wife fell off a chair while he was talking on the telephone]. Now I sit her down in a safe chair with sides.

Husbands in the study substituted their own judgement for that of their spouses in everyday activities. They locked away important items such as jewelry and drivers' licenses, took charge of money, and tried to control wandering or other dangerous behaviors. One man related:

> [Of] course we like to have a social drink, and she used to drink vodka. She'd pour herself a glassful. "It's only water," she'd say, "It's only water." So I locked up the bar.

Caregivers in this group expressed concerns about the loss of dignity suffered by their wives in being unable to care for themselves or cope with normal social situations. One husband described his distress and ambivalence that, on the one hand, his wife seldom thanked him or showed appreciation for his caregiving efforts, yet on the occasions when she was lucid enough to do so, he felt guilty that she was in such a position:

> I'm embarrassed by the fact that she will thank me effusively or kiss my hand. It embarrasses me that she sort of has to stoop to that. She's in a degraded position, and I just hate to see her doing that to herself.

Several husbands reported that they were reluctant to utilize adult day care programs because they felt the atmosphere was demeaning to their spouses. One man described his first impression of the facility as "like a prison." Another subject stated that he had decided not to send his wife to day care because the he did not feel that the program was sophisticated enough for her.

Managing Care

Although most of the men in this study utilized paid supporters to some degree, 2 husbands did not try them at all. One man did not feel comfortable with a stranger in the house, and one said he could not afford the cost because his spouse required round-the-clock care. When these men

could no longer manage to care for their wives without assistance, they chose nursing home placement.

The majority of husbands interviewed for the study delegated at least part of the care of their spouse to others. In conjunction with care management they also became care monitors and care evaluators. They selected home attendants carefully and preferred to do without help rather than have someone who upset their spouse or could not manage her appropriately. One man related that his attempt at using an attendant was disastrous because his wife was very paranoid, would not accept the attendant, and ran away. He then had to worry not only about his wife but about whether the attendant would be able to manage her. He decided not to use a paid helper.

Husbands in the group who found suitable in-home help often expressed considerable anxiety that the individual might leave. They were concerned not only because they would be left without support, but because the attendants were able to do things for their spouse that they could not. One man reported that his helper was able to engage his wife in art work and other activities that he regarded as beneficial for her. Another found that the attendant was able to take his spouse to day care without difficulty, although when he tried to do so, she would cling and refuse to let him leave her. The men who utilized paid helpers found them to be so valuable that they often attempted to

hire more than one individual so that they would have back-up available. One subject had orchestrated an elaborate arrangement, using several attendants on different days of the week as well as a day care center, to ensure not only respite for himself but, equally important to him, that his wife would get out of the house once a day.

The caregivers in this study were especially concerned about the medications that were prescribed for their spouses. The wives were often medicated for agitation or behavior problems, and the husbands perceived their responsibility as not merely to give the medications but to evaluate effectiveness and suggest changes in the type or dosage of drugs if they felt it to be necessary. One man reported that he had successfully reduced the amount of sedation his wife received so that she remained alert but calm. Another husband stated that, when her physician prescribed Valium for his wife, he consulted with his daughter, who was a nurse, and decided that the drug was inappropriate for his wife's symptoms. One caregiver expressed concern that, if he placed his wife in a nursing home, she would be given too much sedation and gave this as one of his reasons for preferring to keep her at home. A man whose wife was in a nursing home intervened when he felt she was oversedated and requested that her medication be reduced.

Changes in the Husband's Life

The husbands who were interviewed for this study found that the trajectory of their lives was dramatically altered. These men experienced profound changes, not only in daily life as caregiving began to consume more and more of their time and energy, but in the construction of the future as well.

Changes in Daily Life

Husbands found that much of their time was spent in providing and managing care of their wives. One man described the constriction of everyday life:

> First we lost the possibility of flexibility in our living, and then the potential for entertaining and going out and doing things.... It was a gradual creeping [thing].

Caregivers in this group found that mealtimes, bedtimes, shopping, and other daily activities were shaped by strategies for caretaking. For the husbands, this meant significant changes in their own lives. They often had to alter patterns of living that had given them great satisfaction. One man explained that, because his wife had begun to fall asleep during the day, he tried to put her to bed very early at night. In order to do this, he had to alter their usual practice of eating a late dinner. She did not notice the change, but for him this meant altering a longstanding and enjoyable habit that reminded him of the

years he had spent living and working in other countries . Another man who preferred a separate bedroom so that he could read at night moved back into his wife's room because she needed help to the bathroom.

For several men in the study, shopping acquired a new purpose as a diversion for their wives. One man described using the nearby shopping mall as a relatively safe, confined area where his spouse could walk. His wife tended to become agitated and run away when upset but could easily be calmed by an invitation to go to the mall. The mall also provided an anonymous setting in which the husband could see and talk with other people without incurring social obligations that he would be unable to repay.

Some husbands used household tasks such as dusting or simple kitchen chores to keep their wives occupied even when it was faster and easier to perform the job themselves. One man explained:

> I try to include her in everything. To keep it the same way. But it's hard for her. [Even] to let her bring the silverware into the dining room, it might end up on the stove.

For other caregivers, the priority was finding ways to prevent interference from their spouses. One man explained that his wife tried to help prepare meals but was no longer able to do so. He found an effective way to restrain her:

> She likes to get up and mess around when I'm cooking. I have to sit her down on the couch. She can't get up from the couch. If she's in her hard chair, she'll get up and come over and walk away with things.

Caregivers found themselves dependent upon the timetables of others. They often had to wait until they could shift the care of their spouses to someone else before feeling free to attend to business or personal needs. In the course of scheduling the interviews for this study, it was apparent that the men had little time for themselves and had to budget it carefully.

Bound Futures

The husbands who were interviewed for this study found that, not only were their daily activities restricted and shaped by the illness of their wives, but plans that they had made for the future were circumscribed as well. They were forced to give up plans that they had made for how and where they would live. Caregivers discovered that their own futures were bound to the restricted futures of their impaired wives.

Several couples had decided to sell their homes and move to retirement residences or life care communities. The husbands found that the illness of their spouses suddenly and effectively ended those plans because the facilities would not accept their wives. One husband said:

> I had to give that up. If this [Alzheimer's Disease] had happened a year later, we'd have been in there now. It happened too fast. She went downhill so fast...I never expected that.

Some of the men in the study were trapped by the financial and legal problems created by their spouses' illness. One man could not sell their home because he had not realized until too late that his wife was no longer competent to sign legal documents, and he was unwilling to obtain a conservatorship for her. Another dared not sell because, so long as he lived in the house, it could not be considered an asset when his wife was evaluated for Medicaid eligibility. If he sold the house, the money would be eaten up, along with the rest of his savings, by nursing home bills.

Relinquishing the Role

The men who were interviewed in this study found it difficult to contemplate giving up the caregiver role. For some men, relinquishing care, even temporarily in order to use overnight or weekend respite programs, was a difficult decision. They were concerned that their wives would be upset without them or would not get proper care. One man described his reluctance to utilize a respite facility:

> I'm working on myself to convince myself that I'm justified to take advantage of that at some appropriate time. It's hard on everybody the

> first few times. To absent yourself. I haven't been absent a single night since she's been ill.... So some combination of guilt or fear or something or other is in you. And others have expressed that to me. It's common. I'm not a freak feeling that way.

Another husband related that his wife had been placed in a convalescent hospital for a short period while he was hospitalized. As soon as he was released, he took her out of the nursing home even though his physician advised him to rest for a few days before resuming caregiving: "It was too hard to take, seeing her there."

Men in the study who were still caring for their wives at home had negative feelings about nursing homes and frequently commented that they did not want to consider nursing home placement because the care would not be acceptable:

> Henry: I think it would do her more harm. I think I'm taking better care of her, and I think it's helping her more.
>
> Paul: I don't want my wife in a nursing home. She won't get the care that I can give her. [She requires] a one on one situation. They'd put her in a wheelchair and put her in front of a window and that would be it.

Six husbands, more than 1/3 of the sample, had placed their wives when they could no longer manage to care for them at home. Two of the women were still living in nursing homes, and 4 had died there. Each of the men related that this was a painful decision, and it was made only when they perceived it to be justified. One husband described his feelings:

> In the first few months, my God, it was awful. I didn't know how I was going to get through it. She'd cry all the time; I'd cry all the time.

Husbands in the study gave a number of reasons for making the decision to place their wives in nursing facilities. One man was concerned about his own increasing frailty and felt that his health would be seriously affected if he continued caregiving. Several men stated that they could no longer lift their spouses. Another husband was concerned for his wife's safety because he was unable to control her wandering. One man felt he could not watch his wife adequately at night and could not give her necessary injections. Still another was concerned that his spouse was noisy at night and bothered neighbors.

Most of the men had two concerns in selecting a nursing home: the quality of care and affordability of care. They wanted to be certain that their spouses would get good care and be as contented as possible. Disregarding his own convenience, one husband chose a facility at some distance

from his home because it offered a fenced yard where his wife could walk outdoors. He then made a daily round trip of 1 1/2 hours to visit her.

The husbands were relieved to find that, in most cases, their wives adjusted relatively quickly to the nursing home environment and were satisfied with the care their spouses received. One man described his feelings about taking his wife to the nursing home. She did not realize that she was going to stay there, and he had no way to make her understand. He was told not to visit for two weeks and experienced considerable anxiety about how she would react when he did go to see her for the first time. He was gratified that she recognized him immediately and greeted him with a hug. Another husband explained:

> There's a certain point where you can put them in a nursing home, and they're not going to be too upset about it. I don't think they really realize what's going on.

A major concern when considering a nursing home was cost. Whether the facility would accept Medicaid influenced most husbands' choice of a facility. The men realized that their savings would diminish quickly, and they would have to get assistance. One man, whose wife had been in a nursing home for six months, commented:

> We picked out two [nursing homes]. One was right here in [town], which was the most convenient for

> us, but they wouldn't accept Medicaid. I knew eventually I was going to have to go to Medicaid because...at $3500 a month, I couldn't handle it. I had $65-70 thousand in the bank, fortunately, but that's getting down around $20 thousand. So I'm getting to the point I've got to find help someplace.

Placement of the wives in nursing homes allowed husbands to give up much of the daily nursing care. However, they did not relinquish the caregiver role. They visited their wives frequently, in most cases daily, and remained very much involved with their spouses.

Although they were aware that they would almost certainly outlive their spouses, the men who were still caregivers had made no firm plans for their lives after their wives died. Several stated that they might like to travel. One man was frank in saying that he would not want to marry again because "there is too much chance of illness and one having to take care of the other." He was adamant that he would not want to be a caregiver again, and he would not want anyone to care for him.

The husbands in this study did not truly relinquish the caregiver role until their spouses died. They then had to construct a future without their wives and also without those responsibilities that had embedded them in caregiving.

Reclaimed and Reconstructed Futures

When they became caregivers, many men in this study were forced to abandon their plans for the future. They not only gave up travel and other leisure plans, but relinquished deeply desired conceptions of their retirement life-style. After their wives died, some of the husbands managed to reclaim or reconstruct the futures they had lost when their wives became ill.

One man related that he and his wife had decided to join an international public service organization and do volunteer work in other countries. When she developed Alzheimer's Disease, he realized that this would not be possible. After her death, he married a woman who shared his interest and recovered that dream with his new wife. Similarly, a man who had suspended his interest in art began to take classes and started to paint. Another man recovered his future in an unusual way. He and his wife were not accepted into a retirement residence because of her diagnosis of Alzheimer's Disease. When she died, he discovered that, without his knowledge, she had placed a deposit on an apartment at the facility they had chosen. He was able to move in immediately.

Other men constructed a different future. A man whose plan had been to operate his ranch as a home for recovering alcoholics related that, when his wife became ill, he had to sell the property. For him this represented not only a loss

of the future but the end of an attempt to recreate the enjoyment of his boyhood on a farm. He had no way to recover what he had lost but, when his wife died, constructed a life that included community service and caretaking on a smaller scale as an attendant to a disabled elderly woman.

Conclusion

In summary of this chapter, men in this study chose to become caregivers of their impaired wives because of the love and mutuality that existed in the relationships with their spouses and as reflections of the norms of reciprocity and solidarity. They began to recognize the changes in their roles when they could no longer normalize or explain changes in their wives, when they realized that their own behavior was changing in response to the dependency of their spouses, or when they were confronted with a medical explanation for the cognitive and functional changes in their wives. The men used these turning points to construct a beginning for their experience as caregivers.

Most men in the study received very limited assistance from family members, friends, or formal support services and were forced to rely on themselves to provide the care needed by their wives. As their spouses became more disabled, caregivers in the study became increasingly embedded in the role. The men found that their daily lives were constricted and shaped by strategies for caregiving, and the plans they

had made for the future had to be substantially altered or abandoned so long as they cared for their wives.

Consequences of role embeddedness will be discussed more fully in the next chapter of the study.

CHAPTER 5

CONSEQUENCES OF ROLE EMBEDDEDNESS

Men interviewed for this study found that caregiving considerably altered the structure of their lives. Becoming immersed in meeting the needs of their impaired wives, they lost the flexibility they once had to engage in social activities. As their wives became more impaired and less able to participate in the life of the couple, husbands were forced to redefine their roles and develop strategies that allowed them to maintain the bond with their spouses.

Social Isolation

Husbands in this study experienced isolation that was both imposed by circumstances and personally chosen. Caregiving activities often consumed the entire day and intruded on sleep at night. For many subjects, the demands of caregiving, described by Gilhooly (1984b) as the "Daily Grind," ensured that they had little time or energy to devote to personal needs or activities. The need to provide constant supervision of the impaired spouse and her inability to tolerate changes in routine often effectively confined the husband to the home and precluded much outside activity. One husband who had been very active in the community explained:

> Well you just have to give up, assign lower or nil priority to a lot of activities you had before. I go to occasional concerts. I do play tennis

occasionally because I do get occasional help here in the house.... So sure, social life is lost. I don't go to meetings that I would like to. A lot of things I'm interested in and have been heavily involved in have just gone by the boards for the time being.

Choosing Isolation

Husbands in this group sometimes chose not to be involved in social activities because their spouses could no longer participate appropriately, and they wanted protect their wives from situations with which they could no longer cope and that might be difficult or embarrassing.

Charles: We don't go out too much because it's difficult for me. It's hard for me. Knowing what she was like.... She would be devastated if she knew what she was doing now. And she would be devastated if she knew I was parading her....

Henry: For her to go out...right across the street, we have an open invitation to go over there. And we used to go over quite a bit. Now she'll go there, and she'll want to get up and go home right away.... It's hard because she was always the center of attraction, and now she wants to be there, but if you're talking to somebody she can't carry on a

> conversation. She gets upset because she can't be part of it.

Changes in Social Relationships

Husbands in this study were also isolated by changes in relationships with friends and family. Friends and family members often disengaged emotionally from the impaired spouse and justified not visiting by wanting to "remember her as she was." One husband explained:

> I know one man in particular...he doesn't want to see her this way. He just doesn't want to see her because he remembers her the way she was. It's like some people won't go to funerals because they don't want to see a person dead. They want to remember the way they were in life. He feels the same way.

However, in disengaging from the impaired wife, friends often isolated the husband as well. Several men expressed a sense of disillusionment because these relationships were not what they had thought. They had expected support from friends and did not get it.

> Jack: It hits you very, very, hard. Friends drop away, relatives drop away. You don't know whether they're scared or indifferent, what it is exactly, but you just don't hear from them. They don't contact you; they don't offer any help. Oh, they'll say, "Let me

know any way I can help," that kind of standard cliche'.

Carl: Well, maybe I'm imagining things, but you find out, at least I've found out you have a lot of friends, but you have fair-weather friends, and you have friends. The people I didn't think were really that friendly are the people that have come through for me and helped me.

Caregiver husbands in this study found that they and their spouses could no longer participate in the same activities or reciprocate in social relationships as they had previously. Several men related that friends tried to continue social activities and outings with their wives, but eventually it became obvious that the women were too impaired. These friendships gradually withered away.

Social activities for many of these men had revolved around parties or taking meals with other couples. These activities gradually became impossible because their wives could not behave appropriately. Caregivers in the study began to realize that they and their spouses were not perceived as a couple in the way that they were before. One man noted sadly that he didn't see former friends, and he didn't think he would be able to resume the relationships even if his wife died because: "They're still couples."

Some husbands in the study were able to continue social contacts with friends on a different basis. They often did not include their wives. One man explained that he had lunch alone with friends and did not take his wife because:

> [She] is kind of disruptive, you know. She has to be fed with a spoon, and she reaches out for things.

Another man explained that he stopped reminding his wife about social events they used to attend together although he sometimes went by himself:

> It's embarrassing in a sense...[friends] don't want to be subjected to being asked the same question 20 times within 15 minutes. And that's exactly the state she's reached.

Some of the husbands who were interviewed reported that relatives and friends often attempted to help by encouraging them to go on with their lives. No matter how well-intentioned, this advice was perceived by husbands as not only impossible to follow, but also as a demonstration of insensitivity and lack of understanding. A man whose family urged him to move and start socializing again after he placed his wife in a nursing home said:

> They sound like it's so easy to do. I have a feeling if they were in my shoes, it wouldn't be much different.

The men were left feeling very much alone because it was clear that other people did not understand their commitment to their spouses. One man explained:

> Well, the vast majority of them wanted me to put her in a convalescent home. "You don't play golf, you don't do this, you don't do that. Put her away. She's never going to recover."

Although most caregivers in the study were disturbed by what they saw as abandonment by friends and family, one man described a temporary feeling of enjoyment in the isolation that he felt:

> In the beginning I sort of thought my caregiving, once I realized that's what I was doing, was in some ways the best time of our lives. We were kind of close together, and...nobody else knew we were in that situation but us. It was a kind of pleasant time. But it didn't last very long.

Husbands interviewed for this study found it difficult to maintain social relationships because they could neither behave spontaneously nor plan activities in advance. Substitution of solitary for group activities was common with these mens. Golf and tennis, hobbies favored by several of the men, require a considerable amount of time as well as scheduling with other players. While several husbands used time purchased for respite to continue these activities, others essentially gave them up in favor of more

flexible endeavors such as bicycling or using home exercise equipment. Reading and listening to music were preferred by others. However, one man commented:

> ...you can do a lot of reading and it's all stimulating and it's good, but you can't sharpen your wits just by reading. You've got to have intercommunication to sharpen your mental processes.

Support Groups

A number of husbands in the study used caregiver support groups to relieve feelings of isolation as well as to get advice on how to manage problems they encountered in caring for their wives. They felt comfortable with others who "knew what they were going through" and reassured that they could ventilate their feelings and use humor to relieve stress without being misunderstood.

The men used a variety of groups including large mixed-sex groups that primarily provided information, small mixed-sex groups, and men-only groups. Most of the men preferred the smaller men's groups because they enjoyed social contact with other men. They also felt outnumbered in mixed groups because they were often the only male among a group of women. A few men preferred mixed groups because they enjoyed the contributions made by women. Several husbands declined to use support groups at all and gave a variety of reasons: The time was inconvenient; they could not leave

their wives; they did not find it helpful and would rather use free time for something else.

Role Redefinition

For the men in this study, the cognitive and memory deficits of their wives irrevocably altered the relationship between themselves and their spouses and disrupted the balance that was created over many years of family life. Their wives were no longer partners and no longer capable of meeting previous role expectations. Boundaries between the roles of husband and wife, as the couples defined them, became blurred when the men began to assume many of the role functions that their wives previously performed. Because of the reciprocal nature of family roles, when the wife could no longer function in the way that she formerly did, the husband had to restructure his own role. Some husbands in the study were surprised and pleased by their ability to adjust and proud of their accomplishments. One man said:

> To the amazement of my family, I've become a housekeeper and a homemaker and chief cook, bottle-washer. Everyone is amazed that [I am] doing all of these things. [I] was rarely seen in the kitchen before. I don't mind that, by the way. I appreciate very much what [wife] did, what any woman does.

For other men who were interviewed the transition was quite difficult and necessitated a profound change in their conception of themselves. They were unused to coping with what is traditionally "women's work." One man described his discomfort in making decisions in an area with which he was unfamiliar:

> What bothers me most is that I don't have her to help me decide about our home. I don't have her to say let's decorate...do this...`cause she had good ideas.

This man also related his dislike of his new status as housekeeper:

> My house has become like a bachelor's house. It's never dusted, and it's never clean. You just use it to live in. And that bothers me a lot. And I hate dusting; I don't want to move things. And I resent not being able to get out and do my work.

Caregivers in the study most frequently reported difficulty in planning and preparing meals. They felt responsible to provide tasty and suitable food for their wives and were not satisfied that their skills were adequate. One husband said:

> That surprised me, that I didn't care for doing it [cooking] and found it difficult. And what's more I didn't do it well, and my wife didn't care for anything I made. She wouldn't eat it.

The men solved this problem in a variety of ways. One couple was eligible for a community meal program and used it several times a week. Other subjects preferred take-out food or frozen dinners, and some hired a home helper to do at least part of the cooking.

Difficulty in Coping With Intimacy

The intensive nursing required by their wives forced husbands in this group into a degree of physical and emotional intimacy that was unfamiliar and sometimes uncomfortable as well. One man said:

> I think that one of the hardest things for a man is that they have to change their way of thinking emotionally. My wife and I, always with one another...we had our privacy. And suddenly there was no privacy. I had to clean her up, and I had to give her a bath and wash her hair. I had to nurture her. That's very difficult for a man. In spite of the fact that you love someone...because it's just not in our nature. Emotionally I don't think we're as strong as women.

Strategies to Manage Intimacy

Some caregivers in the study sought to manage the physical intimacy of nursing care by anticipating and setting limits on what they would or would not do. Incontinence of bowel or bladder was frequently anticipated as beyond the acceptable limit. However, when husbands

actually had to cope with the problem, some were surprised by their own ability:

> I bathed her and changed her Depends. Of course I said, " I'll do everything but that." But I done [sic] it too. It was no big deal. It's amazing what you can do.

However, another caregiver whose wife was in a nursing home said:

> You'd wake up some mornings and it would be an awful mess. If she wasn't incontinent, I'd have her home.

Some husbands were able to shift part or all of the intimate physical nursing such as bathing and managing constipation to paid attendants. Only one man was able to obtain a 24-hour attendant. The others in this group spent long periods of time, especially at night, alone with their spouse and were forced to manage bathing, toileting, dressing, and other intimate care by themselves.

Managing Emotional Dependency

Managing emotional dependency and affectional needs of their spouse was difficult for a number of husbands in this study. Some of the men practiced emotional and physical distancing to reduce their discomfort but paid the price of guilt for doing so:

> Henry: The thing that disturbs me is her dependency on me. I feel that I ought to do more and

meet her needs more than I do. She relies on me more than on the lady we have there. So I try to get out of the house while [attendant] is there because I don't want to make it more difficult.

Charles: We would tell each other that we loved each other and that sort of thing. She will still every once in a while. And I will still, but I do it now more in response to her rather than initiating it. I don't start it off first. I think I'm scarred now. I've been through that sort of thing too much, I guess. And that's bad or not nice or something, but that's the way I feel.

Wives often solicited physical affection, but the husbands were aware of the qualitative difference from the intimacy that previously existed in their marriage and were sometimes ambivalent in response to affectional overtures. One man explained:

> ...I find myself saying, "Come on now, you know I've already given you one [a kiss]." And then I think, My God, what's a kiss? When she was young, boy, you'd love to have that.

Sexual intimacy was also altered by the wife's illness. One man described a period when his spouse displayed an

inordinate interest in sex that was difficult to reconcile with other behavior:

> Well, to be frank, she wanted to make love with me all the time. Even though during the day she'd swear at me. And then that stopped. That's it. That's one of the strange things. I haven't figured out why.

Another husband made a decision to cease sexual activity when it became obvious that sexuality was no longer meaningful to his spouse:

> We don't have any relationship any more. The doctor told me that it was fine to go ahead. But...you know...she's so unaware of it any more, it made me feel like, you know, I was doing something I shouldn't be doing. It made me feel like I was trying to rape her or something.

Loss of Identity As Husband

For a number of the men interviewed, the change in their role was even more definitive because their wives no longer recognized them and validated their identity as husbands. They spent many hours caring for women who did not remember them and often confused them with someone else.

> John: Her memory is gone entirely. I don't think she even knows me. She smiles, "Glad to see you", but if I leave the room she wouldn't even know who's been there, I don't think.

Fred: She gets me confused. She says, "Where has Fred gone?" I say, "I'm Fred." She sometimes finds difficulty remembering I'm her husband. She says, "I didn't know that you're married to me." I say, "We've been married 49 years." And that's what causes me to get testy.

Tom: Of course the loneliness is accentuated because there's no conversation possible with your spouse...she's way back in the past talking about her parents and teachers. She calls me [teacher]. I'm enough older I symbolize teacher...I don't know.

The loss of identity was magnified for some subjects by the loss of their spouses' memories of the past. One husband related that his wife could remember her own childhood, but did not remember their married life and did not recognize their children.

Strategies to Redefine the Relationship

Husbands interviewed for this study often used one or more of a variety of strategies to redefine and recreate a relationship with their spouses that allowed them to continue in caregiving. Some men redefined the relationship as something else. One man, whose marriage had been stormy, described his present feelings for his wife as pity. "If she hadn't been so sick, I would have left her a long

time ago." However, he visited her daily at a nursing home and rejected invitations to visit relatives abroad because he did not feel right in leaving her.

Other men described a parent-child perception of the increased dependency of their wives.

John: Once you get into that position it's like, you know how a mother is with her baby? How they love that baby because they can pick it up and cuddle it? That baby is solely dependent on her. You get that same feeling with your spouse. She's so dependent on me the love becomes more intense.

Dan: When you're taking care of your wife that has Alzheimer's, it's like taking care of a little child.

Many husbands in the study created rituals that served several purposes. Rituals gave pleasure and reassurance to their wives and sometimes helped in managing symptomatic behaviors but also maintained and strengthened the bond between the couple.

Frank: ...I have little games that I play. They're all amused how I get her into a car. It's very difficult so I waltz with her, and I sing "Three O'Clock in the Morning."

Tom: I always kiss her goodnight. I have a

ritual. I kneel down beside the bed and kiss her and tell her goodnight.

Activities such as birthday parties, going out to dinner, going shopping together, going for rides, assumed the character of rituals for some of the men. Husbands continued these activities despite the fact that their spouses did not make memories of these events and in all probability would not miss them if they did not occur.

Men whose spouses were largely unresponsive or did not recognize them often lowered their expectations of the relationship and became adept at reading the small signs of affection and recognition that reflected vestiges of the former bond.

Frank: I hug her and kiss her.... She responds, she'll open her eyes.

Henry: There's still radiant smiles and appreciation. You can sense appreciation.

Fred: She's still affectionate. And sometimes she tells me so. She told me one day when I was washing her down, she told me I was great, just as plain and as clear.... She can't say thanks; she doesn't say thanks any more.

Some subjects separated themselves and their spouses from the changes in personality and behavior by blaming the illness. These men would often preface descriptions of

difficult times with remarks such as: "It's the disease, not the person."

The Theory of Role Embeddedness

The substantive theory of role embeddedness that emerged from this study attempts to define the process by which men become aware of themselves as caregivers and begin to redefine their own roles as husbands. Caregiving is not an expected role transition for older men, and in most cases, they are unprepared for the tasks that are required and the changes that occur in their lives.

For most men in this study, the process began with attempts to normalize or explain changes in the functional status of their wives. Eventually, a "turning point" was reached when it became obvious that the spouse was no longer able to participate as a partner in the life of the couple. The evolving dependency of their wives forced husbands to redefine relationships, not only with their spouses but with family and friends as well, and begin to see themselves as care providers. Once embedded in the role, most men in the study were very self-reliant, defined themselves as the best caregivers for their wives and found it very difficult to relinquish their responsibilities. They retained the role until their spouses died.

CHAPTER 6

DISCUSSION

Summary of Findings

Findings from this study suggest that men become embedded in the role of caregiver both from necessity and from choice. Because husbands in this study received very limited formal or informal assistance, they were forced to rely largely on themselves to provide the care that they wished their wives to have. Despite the intense demands of a role that eventually dominated most aspects of their lives, husbands often defined themselves as the best caregivers for their wives, and most were unwilling to relinquish the role until required to do so by the death of their spouses.

For subjects in this study, becoming embedded in caregiving was a gradual process that began with husbands' attempts to normalize functional and behavioral changes in their wives, and proceeded to a recognition that they were totally responsible for the care and well-being of their spouses. Because the onset of change in their wives was usually subtle and difficult to discern, men in this study often did not identify themselves as caregivers until they reached a point at which they had to recognize that their lives would no longer be same. These "turning points" did not necessarily mark the beginning of caregiving activities for the husbands, but appeared to be self-constructed

benchmarks by which they were able to identify the change in their roles.

For some men in the study, the turning point came when they were faced with dramatic behavioral changes that were precipitated when their spouses were unable to cope with changes in routine or activities. Other husbands in the group gradually assumed increased responsibility for their wives and realized the extent of their spouses' dependency when caregiving activities began to preempt other activities or when they needed help to care for their wives. Some of the men who were interviewed began to define themselves as caregivers when their wives were given a diagnosis, such as Alzheimer's Disease, that the husbands recognized as disabling enough to require a caretaker.

Because the wives suffered from cognitive as well as functional disabilities, the marital relationship was profoundly altered. In order to cope with the changes, some caregivers described the use of strategies such as conversion of the relationship to a parent-child model or use of pity as a basis for continuing the relationship. Other men reported the use of rituals to maintain the relationship and instill meaning into caregiving activities or lowered expectations of the relationship. Some of the men interviewed blamed the illness for changes in the behavior of their wives.

Husbands interviewed for this study reported that their daily lives were constricted by the need to provide constant care and supervision for their wives. Many caregivers found that not only was the present affected by the illness of their spouses, but the future was restricted as well. So long as they cared for their wives, most husbands did not have the freedom to realize plans that they had made to travel, to indulge their interests, or even to move to another residence. For these men, becoming embedded in caregiving meant becoming embedded in the present. Most caregivers were unable to reclaim or reconstruct their plans for the future until their wives died.

Relation of Findings to Literature

This study supports a number of findings from previous research. Prior to becoming caregivers, most husbands were not accustomed to performing housekeeping and nurturing functions that are usually regarded as "women's work". For some of these husbands, this departure from traditional role expectations of men created ambivalence. They sometimes had difficulty with the degree of intimacy required in meeting the physical and nurturing needs of their wives. Some subjects had particular problems in managing incontinence and assisting with functions such as toileting and bathing that may be considered private even in close marital relationships.

The majority of men in the study performed at least some intimate care for their spouses, either from choice or because they had no alternative. As described in the studies by Vinick (1984) and Motenko (1988), husbands interviewed for this study also found that they were able to do the care that was required and expressed a great deal of pride in their accomplishments.

Previous research indicates that male caregivers receive considerable instrumental assistance from their families or from paid support services (Gilhooly, 1984b). Those findings were not consistently demonstrated by this study. Most subjects received little instrumental support from family members. Siblings and in-laws were either unavailable or disinterested. Several men had no children, and many of those who did found that their children could not or did not want to be significantly involved. When family members did provide assistance, they generally did so in limited ways that did not relieve the caregiver husband of the primary responsibility for the care of his spouse.

Snyder and Keefe (1985) reported that caregivers tend to use few community support services even when a variety of services are available. Most husbands in this study used some paid respite services in the form of day care and/or home attendants. However, many subjects could not use these services as much as they would have liked. Husbands gave various reasons for not using formal respite services:

dissatisfaction with available services, mismatch between available services and the needs of their spouses, inability to obtain transportation for their wives, and inability to obtain acceptable attendants. High cost and unaffordability of services was cited by a number of subjects as a barrier to use. Although 7 of the 15 men had relatively high incomes, financial constraints affected both the frequency and type of service they used. Several men were using savings and investment income in order to provide the level of care they deemed appropriate. Cost was also a factor when husbands considered nursing home placement. Most were aware that their assets would eventually be depleted, so they were forced to consider only nursing homes that would accept Medicaid.

This study supports previous research which found that caregivers experience significant social isolation and loss of time for personal activities (Cantor, 1983; Chenoweth & Spencer, 1986; George & Gwyther, 1986; Goldstein et al., 1981). Fourteen of the 15 men in the study reported that their number of social contacts and level of personal involvement in activities had diminished since their spouses became ill. The men indicated that they had to restrict or give up previously enjoyed interests and often substituted activities that did not interfere with caregiving responsibilities. Only 1 husband, who had a live-in home

helper, reported no decrease in his social and community activities.

Most subjects interviewed for the study also stated that they felt abandoned by friends, and sometimes by family, once it became obvious that their wives were impaired. Although most of the men had some friends and relatives who remained in contact, many people did not understand the changes in the wives and no longer socialized with the couple as they previously had. Friends tended to either drop away or to disengage from the wife and socialize on a different basis with the husband.

It was also apparent in this study, that some caregivers may choose to isolate themselves. The men in this study sometimes chose not to socialize, even when the opportunity existed, because they did not wish to expose their wives to situations with which they could not cope. Some men were aware that they and their spouses could no longer function socially as couples and chose not to attend social events by themselves. In some cases, the men acknowledged that they did not wish to expose others to the inappropriate behavior of their wives.

Findings of this study did not support conclusions by Gilhooly (1984b) and Miller (1987) that male caregivers are more likely than women to leave their impaired spouses alone in order not to restrict their customary routines. Subjects in this study were emphatic that they could not leave their

wives alone. In fact, one husband insisted that his spouse remain in the room during the interview because he had to watch her constantly. It was in part because the men would not leave their wives unattended that they were unable to participate in social activities.

Significant research attention has been devoted to the problems of middle-aged women who are forced to balance the demands of marriage and employment with the need to care for elderly relatives (Brody, 1981). Although there is some evidence that the stresses encountered by "women in the middle" may be less typical than was previously believed (Spitze & Logan, 1990), little is known about the prevalence of these role conflicts among men. This study suggests that older men who are caring for disabled wives may, at the same time, be providing considerable support to adult children, and they, too, may be caught "in the middle" between the competing needs of wives and children.

Limitations of the Study

This study was subject to a number of limitations because of the size and composition of the sample. Although every effort was made to obtain subjects who demonstrated a wide variety of experiences, the study did not capture the diversity of the total caregiver population because of the small number of subjects interviewed.

In this, as in other studies of caregiving, subjects were recruited from among caregivers who were known to

health care providers and/or support organizations or groups. The men interviewed had sought assistance with caregiving and had already identified themselves as caregivers. Most subjects were recruited through caregiver support groups. Men who were caring for disabled wives, but refused or did not seek supportive services, might have different experiences from those subjects interviewed for this study.

Health care workers and support group facilitators acted as gate keepers by making initial contact with potential subjects and by obtaining permission to release names of potential subjects to the researcher. Although this approach has the advantage of legitimating the research and perhaps facilitating subjects' agreement to participate in the study, some potential subjects may have been perceived as fragile or uncooperative and may not have been offered the opportunity to participate. Preselection by gatekeepers may have resulted in over-representation of those caregivers who were viewed as coping more effectively, more emotionally or physically healthy, or simply more likely to agree to be interviewed.

Because this was an exploratory study, subjects were sought who were articulate and able to discuss and describe their experiences. The sample was heavily weighted with men who had some college education and could be reasonably expected to meet this criteria. All subjects were white,

and most were recruited from relatively prosperous Bay Area communities. Therefore, findings of this study did not adequately capture the experiences of men who are less well-educated, less affluent, or who are members of minority groups.

Additionally, all subjects were aged 67 or above and were members of a generation whose historical experiences, such as a great economic depression and a world war, may have shaped their life perceptions in ways different from those of younger age cohorts. These men also came from a generation in which the roles of men and women were defined somewhat less flexibly than is presently the case, and in which men were not generally expected to assume caretaking responsibilities.

More than half the men in the study had been married to their wives for 50 years or longer. These long relationships may have influenced their choice to become primary caregivers and contributed to their tenacity in the role. Findings of this study may not reflect the experience of younger age groups whose histories are different, or of men whose relationships have been less enduring.

Another qualification of the study is related to the fact that caregiving is a long term and evolving process. Interviews conducted in this study were largely retrospective and required caregivers to recall experiences that took place over a period of years. Memories of past

experiences may not be entirely accurate due to the passage of time or may be colored by succeeding events. As in any research that is dependent upon interviews, subjects were able to control the information they shared with the researcher and could frame it as they desired.

This was a study of male spouse caregivers. Findings do not necessarily apply to other caregiver groups such as adult children or wives of impaired husbands, and no conclusions can be drawn about differences between men and women as caregivers.

Implications for Clinical Practice

Findings of this study suggest that role embeddedness may be a typical adaptation to the demands of caregiving for husbands whose wives are cognitively impaired. If husbands are to provide the kind of care and supervision that their spouses require, they must assume a new and demanding role that is often poorly understood by family members and social contacts.

Husbands who are primary caregivers appear to be highly motivated and feel a strong sense of responsibility to perform their duties well. Given the patterns of family caregiving that have been described in literature, husbands may be the only family members available to provide the kind of care that their spouses require. Although caregiving presents husbands with significant consequences in terms of financial, emotional, and physical burdens as well as

changes in social and family relationships and alterations of life-style, this study suggests that husbands will frequently choose to become caregivers and will maintain the role as long as they are able.

Husbands interviewed for this study were forced to redefine their relationships with their wives and with friends and family members as well. They discovered that their spouses were no longer partners and could not provide the companionship and support that they previously had. Husbands in this study expressed disillusionment about social relationships and felt abandoned by friends and family members who did not comprehend their experience as caregivers. Nurses can assist these men by validating the importance of their caregiving activities and supporting them as they make the transition to the role. Nurses can also provide support and guidance when husbands are ready to relinquish care of their wives to nursing homes.

Some men in this study experienced discomfort in coping with the new levels of intimacy that were required in order to care for their wives and were ambivalent about meeting the affectional needs of their spouses. Nurses can discuss these feelings with caregivers and reassure them that such thoughts are neither unusual nor wrong.

The majority of men in the study indicated that, prior to becoming caregivers, they knew very little about the illnesses which afflicted their spouses. Most did not

understand the implications of the process of functional and mental deterioration that occurred. Most husbands reported that they obtained little help from physicians in managing the care of their wives. To some degree this may be related to escalating costs and fragmentation of health care services in this country. Few people have the luxury of a family doctor who knows them well and can take the time to discuss management of chronic illness with them. Physicians may also be unprepared to assist or advise caregivers in the daily care of their wives.

Many of the difficulties faced by caregivers are nursing problems related to management of functional deficits and behavioral symptoms such as incontinence, wandering, memory impairments, and personality changes. Nurses who are clinical specialists in geriatrics are familiar with these problems and can provide information and guidance in learning nursing care skills. Nurses can be particularly useful in assessing patients in the home environment and assisting caregivers to develop management strategies that are tailored to the men's specific needs.

A number of men reported difficulty in obtaining a diagnosis for their wives. This was perceived by them as a significant problem. Nurses can assist caregivers, if necessary, in obtaining a diagnosis by referring them to geriatric assessment services or memory clinics that are now available in many communities. Nurses can discuss and

explain the information provided by physicians and may act as liaison between caregivers and physicians in order to facilitate communication.

Caregivers in this study sometimes had difficulty in locating formal support services that met their needs and were accessible to them. Nurses can provide significant assistance in helping caregivers to locate and coordinate appropriate services such as day care centers and support groups where they are available. Nurses may also act as resource persons and advocates for family caregivers to ensure that caregiver needs are appropriately addressed when services are developed.

This study has implications for providers of community respite programs such as day care, and for agencies who provide in-home attendants. A number of caregivers in the study reported that, although they attempted to use respite services, they were unable to do so because, in one way or another, these services did not meet their needs. In some cases, paid caregivers could not manage the wives' behavior or medical symptoms. In other instances, transportation to a respite program was unavailable or inconvenient. Some caregivers did not feel that available programs were appropriate for their spouses. Other husbands reported that when care of their wives became problematic for a community respite service, they were asked to temporarily or permanently withdraw their spouses from the program.

Providers of community programs should be aware that cognitively impaired older adults are a specific population whose needs for care and supervision are different from those of adults who are physically disabled but cognitively intact. Patients should be carefully assessed to determine suitability for a particular program, and personnel should be trained to manage the kinds of patients that are admitted. When patients are accepted into a respite program, providers should make every effort to meet their needs and keep them in the program so that caregivers can feel confident in temporarily relinquishing responsibility. Ideally, a variety of services should be available so that caregivers can choose between a number of options. Attendants should be specifically trained to care for cognitively impaired patients at home. In this study, husbands who had unsatisfactory experiences with community services said that they were reluctant to try those programs again. Careful evaluation of patients' and caregivers' circumstances might minimize negative experiences.

Implications For Nursing Education

As greater numbers of families are faced with the care of dependent elderly members, nurses will increasingly find themselves not only caring for the ill person, but in a position to act as advisors and supporters of family caregivers. Nurses can and should be a major resource for family care providers.

Schools of nursing face the challenge of providing appropriate geriatric nursing experience so that students are prepared for this expanded scope of practice. At present, geriatric content is very limited in many nursing programs, and there is little emphasis on preparing students to assist families that care for dependent elderly relatives at home. Curricula of basic nursing programs should prepare students to care for cognitively impaired older adults and should be designed to sensitize students to the impact of caregiving on family members and to the needs of caregivers.

Graduate nursing programs have the responsibility to prepare nurses for leadership roles in practice, education, and research. Adult and Geriatric Nurse Practitioners and Clinical Specialists, who are educated at the Masters degree level, are often primary care providers and resource persons for elderly patients and their families. This study suggests that husbands who are caring for cognitively impaired wives do have needs for assistance in learning to perform nursing care procedures and in managing the increased levels of intimacy that result from the dependency of their wives. Husbands may also be unfamiliar with tasks related to household management. Students in these nursing programs should be prepared, not only to assess and treat the cognitively impaired women who may be

their patients, but also to identify and address the specific needs of the caregiver husbands.

Doctoral programs in gerontological nursing will provide the pool of future nurse educators and researchers. This study demonstrates that there is a need to prepare instructors who are knowledgeable about the diversity of needs and problems of family caregivers, and can encourage students to develop expertise in this important area of family nursing. The study suggests that the experiences of men who are caregivers offer numerous opportunities for both faculty and student research.

Implications For Future Research

This research was designed to examine how men define and experience the role of caregiver. The study focused on relatively affluent and well-educated white male spouses of cognitively impaired women. Replication of the study with a larger sample that includes men of more diverse educational, economic, and cultural backgrounds would further test and refine the theory of role embeddedness. Studies that compare the experiences of male and female caregivers would help to determine if there are differences between men and women in how the caregiver role is developed and maintained.

Men who become caregivers of impaired wives must make two major role transitions during the process, first when they assume the role and, again, when they relinquish the role upon the death of their wives. Because this research

focused on entering and developing the role of caregiver, the study only briefly touched upon the transition out of the role. Men interviewed for this study relinquished the caregiver role only upon the death of their wives. Further research should be done to describe the experience of caregiver husbands after their spouses have died.

This study of how men perceive and manage the caregiver role provides groundwork for further research focusing on education and support services designed specifically to meet the needs of male caregivers. Clinical researchers might test interventions that assist men in nursing management of their wives. Possible clinical research questions might include: What kind of information is most valuable to male caregivers? What method is most effective in training men to provide nursing care to their wives? Researchers might also investigate the use of support groups by men to determine what factors facilitate or discourage the use of support groups and what types of groups are most helpful to men.

Conclusion

Research has only begun to illuminate the situation of men who assume caregiving responsibilities that have previously been regarded belonging to women. This study of male spouse caregivers sought to explore and describe the ways in which men define and develop a role that is becoming increasingly common for them. In order to provide

supportive interventions for male caregivers, it is important that knowledge about the specific experiences of men be expanded through further research.

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APPENDIX A

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CONSENT TO PARTICIPATE IN A RESEARCH STUDY OF THE EXPERIENCES OF HUSBANDS WHO CARE FOR WIVES WITH DEMENTIA

A. PURPOSE AND BACKGROUND

Dr. Laura Reif and Sharon Lambert, of the School of Nursing, are studying the experiences of men who are caregivers of wives that are suffering from memory problems caused by illnesses such as Alzheimer's Disease. They wish to learn how men feel about caregiving and how they manage problems associated with the care of their spouses.

B. PROCEDURES

If I agree to be in the study, I will be asked to describe my experience as a caregiver and to explain how the illness of my spouse has affected me. I will be asked questions about problems and satisfactions related to the care of my spouse.

These questions will be asked in my home, or at another mutually agreed place, as I wish. The interview will take about one to one and one-half hours. I will be asked for permission to tape record the interview. I may refuse permission for tape recording if I wish.

C. RISKS/DISCOMFORTS

1. Some of the questions may remind me of unpleasant or painful experiences I have had in caring for my spouse, but I can decline to answer questions that upset me and can stop the interview at any time.

2. <u>Confidentiality</u>: Interview records will be kept as confidential as possible. No names will be used in any reports resulting from the study. Information obtained during the interview, including all tape recordings, will be coded, and kept in locked files all the time. Individuals will be referred to by numbers and all identifying information will be removed from notes and recordings. Only study personnel will have access to these files. After the study has been completed and all information has been transcribed from the interviews, tape recordings will be destroyed.

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organization that may have suggested me as a potential participant in the study.

J. TAPE RECORDING OF THE INTERVIEW

I DO/ I DO NOT (Circle one response) consent to tape recording of the interview.

---------　　　　　　　　　------------------------------

Date　　　　　　　　　Study Participant's Signature

Person Obtaining Consent

05/01/90

APPENDIX B
INTERVIEW GUIDE FOR MALE SPOUSE CAREGIVERS

Questions will be asked on the following topics:

Demographic Information

1. What is your age?
   Your spouse's age?

2. How many years have you been married?

3. What level of education do you have?
   __8th grade or less
   __High School Graduate
   __College Graduate
   __Graduate Degree

   What level does your spouse have?
   __8th Grade or less
   __High School Graduate
   __College Graduate
   __Graduate Degree

4. Do you work at present?
   If not, what type of work/career did you have?
   What type of work did your spouse do?

5. What is your family income level?
   __Less than $800/month
   __$800-$1200/month
   __$1201-$1500/month
   __$1501-$2000/month
   __$2001-$2500/month
   __$2501-$3000/month
   __Over $3000/month

6. How would you rate your physical health
   __Excellent
   __Good
   __Fair
   __Poor
   Why do you rate it this way?

7. How many years has your spouse had disabilities related to her memory and thinking?
   Has she been diagnosed with a specific illness?
   What was the diagnosis?
   When was the diagnosis made?

A. In general, has your life changed since your spouse developed (Alzheimer's Disease, MID, etc)?

1. Has her illness affected your hobbies and leisure activities?
2. Have you had to change your plans for the future?
3. Have you had to change your priorities?
4. When did you begin to think of yourself as a caregiver?

B. Has/did your relationship with your spouse changed because of her illness?

1. What about marital and household responsibilities?
2. Are/were there changes in companionship and intimacy?
3. Are/were there changes in activities you enjoyed together?
4. What has remained the same in your relationship with your spouse?

C. Have there been changes in relationships with members of your familiy?

1. have there been changes in behavior of family members toward you and your spouse?
2. Do you still spend the same amount of time and enjoy the same activities with family members?
3. How much help do you receive from family members?
4. Do you have conflicts with family members about your spouse's illness or her care?

D. Tell me about relationships with friends and social acquaintances.

1. Have attitudes and behaviors of friends changed since your spouse became ill?
2. Do you still spend as much time and enjoy the same social activities with friends? With or without your spouse?
3. How do your spouse and friends behave with each other?

E. Tell me about how it is to be a caregiver.

1. What about caregiving is most difficult for you?
2. What is most satisfying?
3. What do you do when you become frustrated or tense?
4. Who helps you when you have problems with caring for your wife?
5. What kinds of community services do you use?
6. How satified are you with the services you use; what problems, if any, do you have in using services?

F. What will happen if you become ill or if your spouse needs more care than you can give?
   1. Who will you ask for help? Will you rely on:
      Family
      Friends
      Formal Services

G. What is special or different about the experience of caregiving for men?
   1. Do men have special problems?
   2. Do men need special kinds of support?
   3. Do/did you participate in a support group?
      If so, how did/does it help you?
   4. Do you think men need to discuss caregiving experiences in a support group with other men only? If so, why?