# FAMILY CAREGIVER MANAGEMENT OF POTENTIALLY PROBLEMATIC SITUATIONS INVOLVING THE CARE RECEIVER WITH DEMENTIA

by

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# Chapter 1: Introduction

## Statement of Problem

Caring for an older family member with dementia can be a very difficult and frustrating experience. The negative consequences of family care for older persons with dementia have been documented repeatedly in the literature (Barnes, Raskind, Scott, & Murphy, 1981; Chenoweth & Spencer, 1986; Deimling & Bass, 1986; George & Gwyther, 1986; Gilhooly, 1984; Greene, Smith, Gardiner, & Timbury, 1982; Haley, Brown, & Levine, 1987; Worcester & Quayhagen, 1983). Several descriptive studies have identified the tremendous emotional strain of caring for older persons with dementia in the home (Coppel, Burton, Becker, & Fiore, 1985; Fuller, Ward, Evans, Massan, & Gardner, 1979; Mann, 1985; Steuer & Clark, 1982). Other research found that caring for someone with dementia adversely affects the caregiver's family, work and social life (Deimling & Bass, 1986; Fitting et al., 1988; George & Gwyther, 1986; Moritz et al., 1989; Sheenan & Nuttal, 1988) and increases the caregiver's risk for negative health outcomes (George & Gwyther, 1986; Haley et al., 1987; Haley, et al., 1988; Moritz et al., 1989; Pett et al., 1989; Pratt, Schmall, Wright, & Cleland, 1985; Rabins, Lucas, & Mace, 1988; Sheenan & Nuttall, 1988).

My own clinical observations suggest that some of the negative consequences experienced by family caregivers occur while managing situations involving behavior problems that are commonly associated with the care receiver's dementia. Previous research in this area revealed that the caregiver's perception of the care receiver's behavior and functional abilities influenced how effectively she[1] was able to manage the behavior problems and mediated the negative consequences she experienced (Harvath, 1986).

The purposes of this study were to identify and define the variables central to a caregiver's management of potentially problematic situations involving the care receiver with dementia and to develop a model that might explain the differences in how effectively the situations were managed. The ultimate goal of this model is to identify, develop, and test nursing interventions to assist caregivers in managing problematic situations involving persons with dementia more effectively and with less strain.

In order to reach that goal, I identified a program of research to: (1) identify and refine the concepts central to the caregiver's management of problem situations involving the care receiver with dementia; (2) develop measures of key concepts identified in this model; (3) test whether this model adequately explains the differences in caregiver effectiveness in managing these situations; and (4) develop and test nursing interventions designed to increase the effectiveness of caregiver management of problem situations

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[1] Because the majority of family caregivers are female, I will use the feminine pronoun to refer generically to caregivers.

involving the care receiver and reduce the strain associated with management of the problems. The research presented here addressed the first step in this program of research.

## Significance of the Problem

In order to understand the significance of the problems in caring for a person with dementia, it is important to look at the effect of dementia on the individual, his or her family, and society.

### Impact on the Individual

An estimated 2 to 4 million (Coughlin & Liu, 1989) Americans suffer from Alzheimer's disease and other dementias, making this group of illnesses the major neuropsychiatric disorders affecting persons over the age of 65 in the United States (Barnes, Raskind, Scott, & Murphy, 1981). Epidemiological research in this area has found the incidence of Alzheimer's Disease to be 520 per 100,000 in the over 65 population (Secretary's Task Force, 1984). The prevalence rate of dementia among those 65 and over is thought to range from 3.9%, for severe cases, to 21.6%, for milder forms (Secretary's Task Force, 1984; White, Cartwright, Cornoni-Huntley, & Brock, 1986). Persons with dementia have reduced life expectancy (Brody, 1982) and usually become completely dependent on others for care as the disease progresses.

The clinical course of dementia is one of progressive, cognitive and functional deterioration. Depending on the extent of disease progression, dementia can result in impairment which ranges from benign memory lapses to decreases in knowledge of current events with disorientation to person, time, and place, to severe cognitive decline, where all verbal abilities are lost and assistance is required in all functional areas (Reisberg, 1984).

As the disease progresses, impairments in memory, judgement, and problem-solving result in increased risks to personal safety. Consequently, persons with dementia eventually require the assistance of others to survive. Although for some individuals, dementia increases their risk for nursing home placement (Wingard, Jones, & Kaplan, 1987; Shapiro & Tate, 1985; Williams & Hornberger, 1984), the majority of persons with dementia are thought to be cared for by families in the community (Secretary's Task Force, 1984; Cohen, Coppel, & Eisdorfer, 1984).

## Impact on Family Caregivers

Informal family caregiving is considered by many to be the linchpin in the delivery of long-term care in the United States today (Reif & Estes, 1982). Shanas (1979) documented the presence and extent of family care for older adults. Despite this evidence, however, the popular myth of family alienation and abandonment of older persons continues, with policy makers urging families to take on even greater responsibility for the care of disabled members (Callahan, Diamond, Giele, & Morris, 1980).

In fact, only about 4 to 5% of persons over 65 years currently reside in nursing homes (Committee on Aging, 1985; Wingard, Jones, & Kaplan, 1987). According to the 1982 National Long-Term Care survey (cited in Stone, Cafferata, & Sangl, 1987), approximately 2.4 million caregivers were providing unpaid assistance to 1.6 million disabled elderly persons who had one or more ADL limitations and who were living in the community. Several authors assert that the presence of a family caregiver is a critical variable in delaying nursing home placement (Brody, Poulshock, & Mascioucci, 1978; Shanas, 1979; Diemling & Poulshock, 1985; Haley, Pardo, & Eastman, 1988).

The strain of caring for older persons with cognitive impairment has been documented extensively. Several studies have correlated caregiver feelings of strain with the common behavior problems related to the dementia (Chenoweth & Spencer, 1986; Deimling & Bass, 1986; Gilhooly, 1984; Greene, Smith, Gardiner, & Timbury, 1982; Haley, Brown, & Levine, 1987; Zarit, Reever, & Bach-Peterson, 1980). A more thorough discussion of the strain of care on family caregivers will be provided later. However, it is important to note here that caring for someone with dementia is thought to exact a tremendous toll on the caregiver's emotional and physical well-being.

The difficulties encountered by families in caring for someone with dementia are thought to be major reasons for nursing home placement of these individuals (Aronson, 1981; Mann, 1985). In fact, 50% of the institutionalized elderly population have been diagnosed with dementia (Wingard, Jones, & Kaplan, 1987). Although it is unclear how much the behavior problems associated with dementia contribute to these statistics, they are suggestive of the heavy strain involved in family care of persons with dementia.

## Impact on the Health Care System

The management of problems associated with family care of older persons with dementia is a growing concern to health care professionals (Beck & Heacock, 1988; Bergmann, Foster, Justice, & Matthews, 1978; Buckwalter, 1988; Eisdorfer & Cohen, 1981). As the number of families who are caring for someone with dementia in the community continues to grow, the need for health care professionals to provide assistance to caregivers will also increase.

Currently, the interventions available to health professionals tend to take the form of education, support, and/or respite. However, the current body of research on the efficacy of these interventions suggests that while these programs seem to have a beneficial effect for some caregivers, they remain limited in their ability to alleviate the negative consequences for a vast number of caregivers (Gallagher, 1985). These programs need to be supplemented with interventions that target specific aspects of caregiving that are associated with negative consequences. Interventions designed to facilitate a caregiver's management of problem situations involving the care receiver would be an important addition to the arsenal of services to caregivers.

Societal Impact

Alzheimer's disease and other dementias have a social impact that cannot be ignored. In addition to the emotional and physical toll of dementia on individuals and families, the economic costs of caring for someone with dementia are considerable. Coughlin and Liu (1989) conducted a study comparing the cost and use of institutional and home care by persons who were cognitively impaired with persons who were cognitively intact. They found that while the cost of care did not differ significantly between the two groups, the use of nursing homes by persons with cognitive impairment was twice that of use by persons who were cognitively intact. They also estimated that while the annual cost of home care of persons with dementia was around $11,700 the annual cost of nursing home care for these persons was $22,300. Because the financial resources of most older persons is depleted rather quickly, the bulk of the financial burden is born by federal entitlement programs (Callahan, Diamond, Giele, & Morris, 1980).

In addition to the direct costs of financing care for persons with dementia, there are indirect losses associated with lost worker productivity. The 1982 National Informal

Caregivers Survey found that although 31% of caregivers are employed, 9% of informal caregivers left the labor force in order to give care (reported in Stone, Cafferata, & Sangl, 1987). An additional 20% reported conflicts between work and caregiving.

### Demographic Trends

Several demographic changes have been predicted that will significantly impact family caregiving to persons with dementia. The most notable change is the increase in the number and percentage of older persons by the turn of the century, particularly the increase in the "old-old", or those over 85 years (Committee on Aging, 1985). This older population is a group that is at increased risk for the development of dementia (Secretary's Task Force, 1984).

At the same time when the demand for family caregiving is expected to increase dramatically, the decreased birth rate of that cohort will provide fewer available caregivers (Day, 1985; Treas, 1977). In addition, it is reasonable to assume that many of those persons "expected" to provide care to the old-old will be aged themselves and possibly experiencing some physical or cognitive disability.

Related to the trend of increased longevity is the high prevalence of frailty of those persons over 85 years (Committee on Aging, 1984). Advances in medical care have been primarily effective in preventing death from acute-onset illness and infections. Similar success cannot yet be claimed in the reduction of chronic illness. In fact, many of those individuals who might have died from complications of their chronic disease process are now able to survive and, consequently, are enduring many more years of disability than in the past. Therefore, the requirements for care for these individuals, at increased risk for dementia, may be of an extended duration.

## Summary of Concerns

The problems associated with family care of older persons with dementia are a growing concern to health care professionals. Predicted demographic changes suggest that although the number of individuals with dementia who need care is on the rise, there may be fewer family resources available to provide that care. In addition, rising health care costs suggest a need to explore less expensive alternatives to institutional care. In order to decrease the risk of institutionalization of persons with dementia and/or reduce the negative consequences for their family caregivers, it is necessary to develop interventions that facilitate the family's provision of care. By finding ways to help family caregivers manage situations involving the behavior problems associated with dementia more effectively, it may be possible to alleviate some of the strain associated with caring for someone with dementia in the community.

# Chapter 2: Review of Literature

Implicit in the research on family caregiving is the assumption that caring for someone with dementia is a stressful situation that results in negative consequences for the caregivers. In particular, management of situations involving the dementia-related behaviors of the care receiver are related to adverse effects for caregivers. However, the negative consequences associated with managing these situations cannot be explained completely by their presence or absence. Consequently, researchers have tried to identify other variables that explain the differential effect of the care receiver's dementia-related behavior on caregivers. In particular, cognitive mediators such as appraisal and coping strategies have been given increased attention in the literature.

The purpose of this review of the literature is to explore the relationships between dementia-related behaviors of the care receiver, the negative consequences of caring for someone with dementia, and the cognitive mediators that seem to intercede between the two. Criteria for inclusion in this review were: (1) research-based articles that focus on two or more of the concepts of interest; and (2) articles published between 1980 and the present. These articles have been summarized in Tables 2.1, 2.2, and 2.3. I will organize this review by first analyzing the empirical results related to each of the major concepts: dementia-related behavior, negative consequences, and cognitive mediators. Next, I will explore the relationships among these concepts. Finally, I will summarize the major themes in the literature and identify some areas that warrant further research.

## Dementia-Related Behavior

A number of researchers have explored the role of dementia-related behavior of the care receiver in the development of negative consequences for caregivers (see Table 2.1). In almost every study, dementia-related behavior of the care receiver is correlated with negative consequences for the caregiver. In fact, in studies where the effects of dementia-related behavior of the care receiver is compared with the effects of other aspects of impairment (e.g., cognitive, functional, or social), the care receiver's behavior is more predictive of many of the negative consequences for the caregiver than the other types of impairment.

Still, the relationship between dementia-related behavior and other types of care receiver impairment is complex, conceptually and methodologically. On the surface, authors who separate care receiver impairment into four dimensions, cognitive, behavioral, social and functional, seem to provide conceptual clarity that is desirable in understanding how the different aspects of the care receiver's impairment influences the caregiver. Indeed, studies that have looked at these dimensions separately have found differential effects on caregivers (Deimling & Bass, 1986; Pearson, Verma & Nellett, 1988; Haley, Brown, & Levine, 1987).

In reality, however, those dimensions may not be so distinct. For example, many researchers define decreased memory and disorientation as cognitive deficits. Still, the care receiver may manifest these deficits behaviorally with frequent queries about the time, by insisting on "going home", or by not recognizing the caregiver. Similarly, a care receiver's deficits in ADL function may occur because of deteriorating cognitive abilities, or may be a result of resistance to care. These subtle differences may have important implications for the development of negative consequences for caregivers.

The care receiver's dementia-related behavior has been measured using a variety of tools that reflect aspects of the behavior thought to create difficulties for the caregiver. In general, these instruments provide a list of "problematic" care-receiver behaviors and ask the caregiver to rate how often the behavior occurs (Deimling & Bass, 1986; Gilleard et al., 1984; Haley, Pardo & Eastman, 1988; Haley Levine, Brown, & Bartolucci, 1987; Haley, Brown, & Levine, 1987; Pearson, Verma & Nellett, 1988; Poulshock & Deimling, 1984; Pruchno & Resch, 1989; Quayhagen & Quayhagen, 1988; Rabins, Mace & Lucas, 1982; Sheenan &

Nuttall, 1988; Zarit, Reever, & Bach-Peterson, 1980; & Zarit, Todd & Zarit, 1986). Implicit in these instruments is the assumption that the dementia-related behaviors are, in and of themselves, problematic or disruptive for caregivers.

Also implicit in these instruments is the assumption that dementia-related behaviors that occur more frequently create more problems for caregivers than behaviors that occur less often--an assumption not substantiated in the literature. These assumptions are important for two reasons. First, the assumption that the dementia-related behavior is problematic clouds our understanding of what it is about the behavior and the context in which it occurs that is problematic for the caregiver. For example, based on clinical experience, we know that dementia-related behavior that occurs at night and interferes with the caregiver's sleep is often more problematic than behaviors that occur during the waking hours. Similarly, dementia-related behaviors that put the care receiver at risk for injury or are unpredictable are often bigger problems than less hazardous behaviors or behavior that occurs predictably. By measuring only how often the dementia-related behavior occurs, we may be masking more salient characteristics of the behavior that would help explain the strain it causes for the caregiver.

A second problem with the assumption that the dementia-related behaviors are, a priori, problematic confounds the behavior with the caregiver's reaction to it. Again, from clinical experience we know that while some caregivers perceive some dementia-related behaviors to be problematic, others do not. It is important to distinguish salient aspects of the care receiver's dementia-related behavior and the situation in which it occurs from the caregiver's perception of the behavior.

Related to the conceptual issues involved in the definition of the care receiver's dementia-related behavior are methodological issues involving measurement. While the care receiver's functional and cognitive abilities are often measured objectively by someone from the research team, the dementia-related behaviors of the care receiver are measured by interviewing the caregiver about the presence or absence of behavior problems. Again, this measurement technique may confound the care receiver's behavior with the caregiver's perceptions of the behavior.

Finally, the literature remains divided on what constitutes a complete or representative list of dementia-related behaviors. For example, the instrument developed by Zarit, Reever, & Bach-Peterson (1980) lists 28 memory and behavior problems frequently associated with dementia. Included on that list are disruptive behaviors, deficits in cognition, and impairments in functional ability. In contrast, the tool by Deimling & Bass (1984) contains only seven items measuring the care receiver's "acting out" behaviors. As noted earlier, these distinctions may be somewhat artificial.

## Negative Consequences of Caregiving

A number of researchers in the area of family caregiving for someone with dementia focused on identifying, defining, and measuring the negative consequences of caregiving (see Table 2.1). While some investigators used the terms caregiver burden, strain, and stress interchangeably, others have drawn sharp distinctions between the concepts (for further discussion of this issue, see for example Montgomery, Stull, & Borgatta, 1985; Knapp, 1988; Stagner, 1981). Still others added more specific problems to the growing list of adverse effects thought to result from caregiving (e.g., depression, changes in physical health, decreased well-being, financial strain, restricted caregiver activities etc.). In this next section, I will briefly describe five general categories of negative consequences associated with caring for someone with dementia. I will also discuss some of the conceptual issues relating the care receiver's dementia-related behavior to negative consequences for caregivers.

An analysis of the literature reviewed here suggests that the negative consequences of caregiving for the caregiver can be grouped into five categories: physical health problems, decreased mental health (e.g., depression, burden, distress), lifestyle or activity changes (e.g., restriction of activities, financial strain), changes in the care receiver's relationships with the care receiver and others, and decremental changes in caregiver well-being (e.g., decreased morale and life satisfaction).

### Physical Health

Physical health problems associated with caring for someone with dementia include a wide range of acute and chronic illnesses. Although specific aspects of the caregiving situation have not been associated with specific physical health problems, it is assumed that the cumulative effect of caring for someone with dementia, particularly in the later stages, exacts a significant toll on the physical health of the caregiver.

### Mental Health

A number of mental health problems have also been associated with caregiving (see Table 2.1). Problems cited most frequently include caregiver burden or strain, depression, and distress. It is important to note that while researchers generally use standard measures of depression and other psychological symptoms not specifically designed for caregiver research, measures of burden and strain are developed solely for use in caregiver research.

There are advantages and disadvantages for each set of measures. For example, standard measures of depression generally have norms established with criteria that help to determine whether the subject's depression is clinically significant. These are useful data to have to determine how caregivers compare with non-caregiving controls, and whether the levels of depression associated with caregiving are significant. To date, no such normative data exist for measures of burden or strain. This makes it more difficult to interpret how significant are the scores on measures of burden.

In contrast, measures of caregiver burden and strain are usually designed to address the aspects of caregiving that are thought to be associated with negative consequences for the caregivers. This helps to provide a better understanding of the dynamics between the stressful situation and the adverse effect it has on the caregiver. Measures of depression and other psychological variables do not relate to aspects of the caregiving situation per se. Consequently, it is more difficult to understand what aspects of the situation are most pathogenic for caregivers. In addition, it is not always clear whether the depression is related to the caregiving situation at all. Instead, it may relate to other events in the caregiver's life.

### Changes in Lifestyle

Changes in the caregiver's activities and lifestyle are another set of important negative consequences that result from caregiving (George & Gwyther, 1986; Moritz, Kasl, &

Berkman, 1989; Poulshock & Deimling, 1984; Sheenan & Nuttall, 1988). These changes usually include a restriction of the caregivers social and leisure activities, demands that interfere with employment, or financial strain due to increased expenses involved in providing care to a dependent family member.

## Negative Family Relationships

Caring for someone with dementia has also been shown to have a negative impact on the caregiver's relationships with significant others (Deimling & Bass, 1986; Fitting, Rabins, Lucas, & Eastham, 1986; Pearson, Verma and Nellett, 1988; Poulshock & Deimling, 1984). Here again, it must be questioned whether it is caregiving that causes problems in family relationship, or whether having other family responsibilities causes caregiver burden.

## Decremental Changes in Well-being

Several authors have investigated the impact of caregiving on various measures of well-being (George & Gwyther, 1986; Gilhooly, 1984; Haley, Pardo, & Eastman, 1988; Haley, Levine, Brown, & Bartolucci, 1987; Motenko, 1989; Pett, Caserta, Hutton, & Lund, 1988; Quayhagen & Quayhagen, 1988). In addition to the negative consequences associated with caregiving, these researchers have found that caring for someone with dementia reduces the caregiver's morale, life satisfaction, and sense of general well-being.

These measures are useful because, like standard measures of depression, they allow a comparison of caregivers with non-caregiving normals. According to George & Gwyther (1986), this allows one to determine the total net effect of caregiving on caregivers. These measures are limited in that they provide little information about the aspects of caregiving that reduce well-being.

### Conceptual Issues of Negative Consequences

It is important to note that although different types of negative consequences have been identified for caregivers with dementia, the conceptual basis for their selection is not clear. In addition, there is not complete agreement between investigators about which are consequences of caregiving, and which are correlates that help to explain why some caregivers experience negative consequences and others do not. Although these distinctions are subtle, they are important in order to better understand the complexity of the caregiving situation.

In most of the research cited in Table 2.1, the rationale for choosing one negative consequence in favor of others is generally not provided. The notable exceptions include the research by Haley and associates (1987, 1988), Cohen & Eisdorfer (1988), and Coppel, Burton, Becker, & Fiore (1985). In those studies, the choice of variables was specified by the theoretical frameworks used to explain the caregiving phenomena. In contrast, most research in this area lacks a clear conceptual base. This is not a harsh criticism of the literature, but instead reflects the relatively early development of our understanding of the dynamics involved in caring for someone with dementia. Indeed, these studies have provided important information regarding the caregiving situation.

The evidence reviewed here suggests there is a rather selective relationship between measures of care receiver impairment and the negative consequences for caregivers. For example, while impairments in ADLs seem to be related to restrictions in caregiver activities (Deimling & Bass, 1986; Moritz, Kasl, & Berkman, 1989), dementia-related behaviors of the care receiver seem to be more related to negative changes in the caregiver's mental health (Deimling & Bass, 1986; Pett, Caserta, Hutton, & Lund, 1988; Pearson, Verma, & Nellett, 1988). Still, the selective nature of these relationships does not entirely explain differences in caregiver experience.

In order to better understand the dynamics involved in negative consequences for the caregiver, several authors have suggested that other variables must be considered. A number of researchers have identified demographic, situational, and interpersonal variables that are thought to influence the difficulties encountered in caregiving (see Table 2.3). For example, gender is thought to influence the negative consequences experienced by caregivers. However, it is not clear whether it is gender itself or differences in the nature of the caregiving role assumed by men and women that makes a difference.

Chenoweth and Spencer (1986) found that negative consequences from caregiving seem to change over time. Early in the progression of the dementia, the episodic occurrences of problem behaviors and other impairments made it difficult for caregivers to understand that changes in the care receiver's behavior and personality were related to the dementia. This suggests that the caregiver's understanding of the course and progression of dementia may influence how she perceives and interprets the care receiver's behavior, influencing the negative effects she experiences. A better understanding of the variables that influence the negative consequences from managing the care receiver's dementia-related behaviors is needed.

## Mediators of Negative Consequences of Caregiving

A number of researchers have identified variables that are thought to mediate the relationship between stressful aspects of the caregiving situation and the negative consequences that result for the caregiver (see Table 2.2). These variables are thought to either buffer or attenuate the negative consequences of caregiving. In general, these mediator variables usually fall into two categories: interpersonal and intrapersonal mediators.

## Interpersonal Mediators

Interpersonal mediators include social support, the quality of the caregiver-care receiver relationship, and formal services. Caregivers who have a supportive social network, a good relationship with the care receiver, and/or who have access to formal services are thought to experience fewer untoward reactions to stressful caregiving situations than other caregivers.

In general, these hypotheses are substantiated in the literature. For example, a supportive social network does seem to buffer the negative effects of caregiving (Baillie, Norbeck, & Barnes, 1988; Quayhagen & Quayhagen, 1988; Scott, Roberto, & Hutton, 1986).

It is noteworthy, however, that although many researchers have noted the important role social support plays in reducing the negative consequences of caregiving, many do not describe it as a mediator between specific aspects of the caregiving situation and the caregiver's adverse reaction to them (Coppel, Burton, Becker, & Fiore, 1985; Fitting, Rabins, Lucas, & Eastham, 1986; George & Gwyther, 1986; Gilhooly, 1984; Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984; Pett, Caserta, Hutton, & Lund, 1988; Poulshock & Deimling, 1984; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986). Instead, they are viewed as having a more general effect that correlates with decreased levels of burden, depression, and/or distress.

The effect of formal services on the negative consequences of caregiving was not examined in this review of the literature. It is important to note, however, that, as pointed out earlier in this proposal, these services have generally not been successful in alleviating the untoward effects associated with caring for someone with dementia.

### Intrapersonal Mediators

Intrapersonal mediators include the caregiver's cognitive or affective interpretations (called attributions or appraisals) of the situation and the coping efforts she uses. They serve as psychological buffers between the stressful situation and the caregiver's negative reaction to it. Based on previous research and clinical experience with family caregivers, these intrapersonal mediators are particularly important in the caregiver's management of dementia-related behaviors of the care receiver.

The studies reviewed here supported the hypothesis that cognitive mediators in general, and appraisal in particular, help to explain the differential effect of the care receiver's dementia-related behaviors on the caregiver's experience (Baillie, Norbeck, Barnes, 1988; Cohen & Eisdorfer, 1988; Coppel, Burton, Becker, & Fiore, 1985; Haley, Pardo, & Eastman, 1988; Haley, Levine, Brown, & Bartolucci, 1987; Haley, Brown, & Levine, 1987; Hirschfeld, 1978; Hirschfeld, 1981; Motenko, 1989; Poulshock & Deimling, 1984; Sheenan & Nuttall, 1988). In addition, coping strategies used by the caregiver were found to influence the negative consequences associated with caregiving (Haley, Pardo, & Eastman, 1988; Haley, Levine, Brown, & Bartolucci, 1987; Haley, Brown, & Levine, 1987; Pett, Caserta, Hutton, & Lund, 1988; Pratt, Schmall, Wright, & Cleland, 1985; Quayhagen & Quayhagen, 1988; Scott, Roberto, & Hutton, 1986).

In general, the intrapersonal mediators thought to be important to caregiver research reflect two distinct schools of thought. First, the research by Cohen & Eisdorfer (1988) is based on the assumption that caregivers have different, yet stable, attributional styles. In other words, some caregivers tend to attribute the problems they encounter in caregiving to external causes, while others attribute them to internal causes. Certain styles are thought to relate more to negative outcomes than other styles. They found no significant correlations between attributional styles and depression.

In contrast, the research by Haley and associates (1987, 1988), Coppel, Burton, Becker, & Fiore (1985) and Motenko (1989) is based on the assumption that different stressors evoke different appraisals or attributions by caregivers. Presumably, the stressor and the situation in which it occurs influences the type of appraisal made by the caregiver. In all of these studies, significant correlations in the predicted directions were found between the stressors, the appraisals, and the negative consequences for the caregiver. These findings support the notion that appraisals made by the caregiver mediate the negative sequelae of caring for someone with dementia.

What is not clear from this review is what is involved in the appraisals made by caregivers. The work by Cohen and Eisdorfer (1988) suggest that the caregiver's attribution of causality plays an important role in the development of negative effects from caregiving. Haley and associates focus on the caregiver's perception of how stressful the situation is and how confident they are they can manage it. Shoemaker (1986) reports that the caregiver's perception that the care receiver's dementia-related behavior reflects some continuity from the past makes an important difference in how much stress is associated with the behavior.

In addition, Hirschfeld (1978, 1981) found that mutuality between the caregiver and care receiver enhanced the caregiver's ability to continue caring for the care receiver. Although mutuality would, at first, appear to be an interpersonal mediator of stress, Hirschfeld defines it as the caregiver's ability to find gratification in the relationship with the care receiver and meaning in the caregiving situation. This perception by the caregiver may be independent of the actual quality of the relationship between her and the care receiver.

Taken together, these different conceptualizations of intrapersonal mediators suggest that caregiver appraisal is a multi-dimensional concept that plays an important role in mediating the negative consequences associated with the care receiver's dementia-related behavior. A better understanding of the dimensions of appraisal and their relationship to other variables central to caring for someone with dementia is needed.

## Level of Abstraction

This review of the literature revealed that the measures of the negative consequences associated with caring for someone with dementia reflect three different levels of abstraction. Some of the measures (e.g., depression and well-being) were global and did not relate directly to the caregiving situation. Instead, it was presumed that by measuring depression in a caregiver, it was possible to measure the depression resulting from caregiving.

A second set of measures relates to the caregiving situation in general (e.g., Zarit Burden Interview). These measures assume that caregiving is a generally stressful situation that creates burden or strain for caregivers. Included in these scales are items that measure the negative consequences that result from the caregiving situation in a general way.

A third set of measures of strain or burden were directed at specific aspects of the caregiving situation. For example, Pearson and associates developed measures of distress that corresponded directly to measures of care receiver impairment. These measures focused on the negative consequences from specific classes of care receiver impairment or specific types of problems in caregiving.

The issue of which level of abstraction to use in research on caregivers is important in understanding the complexity of the concepts central to caregiving. In part, the choice must reflect the purpose of the study. If one is interested in comparing caregivers with non-caregivers, then measures of general well-being seem to be most appropriate (George & Gwyther, 1986). In contrast, if one is interested in understanding why certain dementia-related behaviors are associated with problems for some caregivers, a more specific level of analysis is warranted.

In addition, the results from the studies reviewed here suggest that it may be important to measure and analyze data within a consistent conceptual level. For example, general measures of care receiver impairment tended to explain general measures of negative consequences for caregivers better than specific measures of impairment. Likewise, more specific measures of care receiver impairment were, in general, more highly correlated with more specific measures of negative consequences for caregivers.

## Summary of Review of the Literature

Based on this review of the literature, several conclusions about the phenomena of caring for someone with dementia can be drawn. First, an analysis of the evidence presented here suggests that dementia-related behavior of the care receiver is indeed associated with increased negative consequences for caregivers.

Still, there are some gaps in our understanding of the role of the care receiver's dementia-related behaviors in the development of negative consequences for caregivers. In order to understand fully why certain dementia-related behaviors are problematic for some caregivers, the salient aspects of the care receiver's behavior and the situations in which it occurs must be specified.

In addition, a better understanding of the how these behaviors relate to the care receiver's social, functional and cognitive impairments is needed. It also seems important to distinguish between the care receiver's dementia-related behavior and the caregiver's perception of, and reaction to, the behavior. This may help us develop and target interventions that help caregivers manage the care receiver's dementia-related behaviors more effectively and with less strain.

This review of the literature also suggests that the relationship between the care receiver's dementia-related behavior and the resultant negative consequences for caregivers is complex. Although the nature of the relationships between these two sets of variables is not completely clear, they seem to be selectively correlated. For example, dementia-related behavior of the care receiver is more highly correlated with mental health problems for the caregiver than physical health problems. In addition, similar dementia-related behaviors cause different degrees of problems for different caregivers.

The dynamics of the selective relationship between dementia-related behavior of the care receiver and negative consequences for the caregiver is not well understood. Many authors now believe that the caregiver's appraisal of the care receiver's dementia-related behavior explains the differential effects of the behavior. However, our understanding of the caregiver's appraisal of the care receiver's dementia-related behavior remains limited. In particular, we know very little about what aspects of the caregiver's appraisal are salient, how the appraisal influences the caregivers efforts to manage the behavior, and how the appraisals and coping efforts relate to the negative consequences she experiences. The research presented here provides some insight into the role of caregiver appraisal of dementia-related behaviors in the development (or lack thereof) of negative consequences from managing those behaviors.

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Authors | Study Design | Sample Size & Type |
|---|---|---|
| 1. Baillie, Norbeck, Barnes (1988) | 1. Descriptive Correlational | 1. Convenience sample of primary caregivers providing care in home, recruited from county support groups (n=87) |
| 2. Cohen & Eisdorfer (1988) | 2. Descriptive Correlational | 2. Convenience sample of 46 caregivers for 27 patients with clinically diagnosed with Alzheimer's Disease recruited from agencies and clinicians |
| 3. Coppel, Burton, Becker, & Fiore (1985) | 3. Descriptive Correlational | 3. Convenience sample of spousal caregivers to 47 non-institutionalized and 21 institutionalized persons |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Behavior Measure | Mediators of Negative Consequences | Measures of Negative Consequences of Caregiving |
|---|---|---|
| 1.Not measured | 1. (a) satisfaction with social support: 8-item questionnaire; (b) perceived stress: 16-item tool developed from review of the literature; measures stress from care receiver's behavior, communication, emotional/ mental status, and relationship with caregiver | 1. Psychological distress & depression: POMs, 65-item adjective rating scale |
| 2. Not measured | 2. 6-item scale measuring attributional style dimensions of locus of control, stability, and globality | 2. (a) depression: Beck Depression Inventory (BDI); clinical evaluation by psychiatrist; (b) distress: single-item rating |
| 3. Predictability of care receiver's behavior | 3. Caregivers attributions regarding (a) causes of behavior problems, (b) coping abilities, and (c) success of coping efforts; obtained through open-ended questions and multi-item scales | 3. Depressive symptoms: BDI & SADS-C |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Other Variables Measured | Results | Comments |
|---|---|---|
| 1. Demographic variables, characteristics of caregiving situation, mental function of care receiver | 1. Perceived stress correlated with increased mental and functional impairment of care receiver, depression, distress, and decreased satisfaction with social support; decreased satisfaction with social support correlated with functional impairment of care receiver, hours of care needed, psychological distress & depression; perceived stress accounted for 21% of variance in psychological distress and 24% of variance in depression; satisfaction with social support accounted for 10% of variance in psychological distress and 12% of variance in depression | 1. Both intra-and interpersonal mediators seem to buffer the negative consequences of caregiving; they may have a selective effect on these consequences |
| 2. Demographic variables, living situation of care receiver | 2. Perceptions of internal locus of control, stability or globality of causes of stress not related to depressive symptoms; caregivers who were depressed thought they should have more control over events than caregivers who were not depressed | |
| 3. Initial symptoms of dementia; implications regarding diagnosis, reactions of caregiver's social network to diagnosis, philosophical causality | 3. Attributions of stability and globality correlated with scores on BDI; cognitions about unpredictable behaviors and life change correlated with depression; cognitions about coping ability and success correlated with depression scores | 3. Cognitive processes related to specific situations may provide more of a buffer than attributional styles of the caregiver |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Authors | Study Design | Sample Size & Type |
|---|---|---|
| 4. Deimling & Bass (1986) | 4. Descriptive Correlational | 4. Purposive, stratified sample of spouse and daughter caregivers from 120 referral agencies (n-586) |
| 5. Fitting, Rabins, Lucas, & Eastham (1986) | 5. Descriptive Correlational | 5. Convenience sample of spouse caregivers (n=28 husbands and 26 wives) |
| 6. George & Gwyther (1986) | 6. Descriptive Correlational | 6. Non-random sample of caregivers from statewide dementia mailing list (n-510) |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Behavior Measure | Mediators of Negative Consequences | Measures of Negative Consequences of Caregiving |
|---|---|---|
| 4. 7-item scale focusing on care receiver's acting out behaviors | 4. Not measured | 4. 11-item scale measuring megative changes in family relations; 5-item scale of restricted activities; single item of physical helath changes; Zung Depression Scale |
| 5. Not measured | 5. Not measured | 5. (a) Zarit Burden Interview (ZBI); (b) Family Environment Scale (FES); (c) 9-item social network scale; (d) MMPI; (e) three open-ended questions about the caregiving experience |
| 6. 32-item scale of symptoms of dementia from the literature | 6. Not measured | 6. Changes in well-being: (a) physical health: number of physician visits past 6 months, single item self-rated health; (b) mental health: Affect Balance Scale, Short Portable Psychiatric Evaluation Schedule, single-item on life satisfaction, presence of psychotropic drug use past 6 months; (c) social participation: frequency of family phone contacts & visits, amount of leisure time, satisfaction with leisure; (d) financial resources: household income, multi-item scale of economic well-being |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Other Variables Measured | Results | Comments |
|---|---|---|
| 4. ADL impairment, social functioning of care receiver, cognitive incapacity | 4. Path analytic models using 4 measures of care receiver impairment explained 48% of variance in negative family relations, 14% of the variance in health, 13% of the variance in depression, and 11% of the variance in restricted activities; disruptive behavior had the strongest direct effects on family relations (B=.54) and depression (B=.23) | |
| 5. Functional impairment of care receiver, social network, change in marital relationship | 5. No differences between men and women on FES, social networks, or burden; women experienced more depression, hysteria, and paranoia | |
| 6. Relationship to care receiver, living arrangements, caregiver perceived need for social support, duration of dementia | 6. Caregivers averaged 3 times as many stress symptoms, had lower affect balance levels, lower life satisfaction, used more psychotrophic drugs, and pursued lower preferred level of social activity than when compared to normative data; severity of care receiver symptoms related to lower caregiver health, higher stress, and less leisure time for caregiver | |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Authors | Study Design | Sample Size & Type |
|---|---|---|
| 7. Gilhooly (1984) | 7. Descriptive Correlational | 7. Convenience sample of resident (n=20) and non-resident (n=17) caregivers from two Scottish day hospitals |
| 8. Gilleard, Belford, Gilleard, Whittick, & Gledhill (1984) | 8. Descriptive Correlational | 8. Convenience sample of caregivers for persons referred to or attending a day hospital (n=227) |
| 9. Haley, Pardo, & Eastman (1988) | 9. Longitudinal | 9. Convenience sample of 48 caregivers |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Behavior Measure | Mediators of Negative Consequences | Measures of Negative Consequences of Caregiving |
|---|---|---|
| 7. Modified Crichton Royal Behavioral Rating Scale (information not available) | 7. Not measured | 7. (a) morale: Kutner Morale Scale; (b) mental health: OARS mental health scale |
| 8. 7-item subscale measuring behavioral distrubance and demand | 8. Not measured | 8. General Health Questionnaire (GHQ), 30-item scale measuring psychiatric disorders |
| 9. Memory & Behavior Problems Checklist (MBPC) | 9. (a) appraisal of stressfulness of behavior problems, ADL & IADL impairment<br>(b)self-efficacy regarding ability to manage each of the behavior and functional impairment problems; (c) coping strategies | 9. (a) depression: BDI; (b) life satisfaction: Life Satisfaction Inventory (LSI-Z); (c) relationship; (d)Health status Questionnaire; (e)self-rated health |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Other Variables Measured | Results | Comments |
|---|---|---|
| 7. Mental status of care receiver, ADL/IADL impairment, frequency of contact with famliy members, social resources, satisfaction with help, formal services, quality of caregiver-care receiver relationship | 7. Low caregiver morale associated with female caregivers, male care receivers, and fewer nurse visits; low mental health associated with decreased satisfaction with help, closer blood/role relationship, less home health services, and co-residence status | |
| 8. Contact with care receiver, family support, services, quality of past and present relationship with care receiver, course and development of dementia | 8. Approximately 50% of the sample had clinically significant psychiatric diagnoses; 48% of the variance in GHQ scores explained by caregiver health ratings (31%), care receiver behavioral disturbance (14%) and quality of past relationship (3%) | 8. Comparison of GHQ scores with psychiatrist evaluations revealed significant number of false negatives and false positives |
| 9 Duration of dementia, mental status, ADL/IADL impairment, placement at time 2 | 9. Although patient death at time 2 related to greater initial impairment, nursing home placement related to caregiver variables at time 1; increased behavior problems at time 1 related to nursing home placement at time 2; appraisal of increased stressfulness of behavior problems and decreased self efficacy to manage them at time 1 related to nursing home placement at time 2 | |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Authors | Study Design | Sample Size & Type |
|---|---|---|
| 10. Haley, Levine, Brown, & Bartolucci (1987) | 10. Descriptive correlational | 10. Convenience sample of primary caregivers with at least weekly responsibilites for a care receiver who scores <24 on the MMS, recruited from local agencies and ADRDA (n=54) |
| 11. Haley, Brown, & Levine (1987) | 11. Descriptive correlational | 11. Convenience sample of primary caregivers for a care receiver who lives in the community and scores <24 on the MMS, recruited from local agencies and ADRDA (n=44) |
| 12. Moritz, Kasl, & Berkman (1989) | 12. Descriptive correlational | 12. A representitive sample of non-institutionalized elderly and their spouse caregivers (n=318) |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Behavior Measure | Mediators of Negative Consequences | Measures of Negative Consequences of Caregiving |
|---|---|---|
| 10. MBPC | 10. (a) appraisal of stress: 3-point rating scale for each item on the ADL, IADL, and MBPC scales; (b) self efficacy: 3-point rating scale corresponding to items on ADL, IADL, and MBPC, measuring caregiver's confidence in managing the problem; (c) coping: Health & Daily Living Form (HDLF), multi-item scale measuring 5 types of coping; (d) social support and activites: HDLF | 10. (a) depression: BDI; (b) life satisfaction: LSI-Z; (c) self-rated health |
| 11. MBPC | 11. see above | 11. Not reported |
| 12. Not measured | 12. Not measured | 12. (a) caregiving burden: CES-D depression scale; (b) caregiving impact: multi-item scale of social functioning, sleep complaints, Kats ADL scale, and 9-item scale measuring chronic conditions |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Other Variables Measured | Results | Comments |
|---|---|---|
| 10. ADL/IADL impairment, cognitive impairment, duration of cognitive impairment, percent of caregiver responsibility, demographic variables | 10. Stressors & demographic variables showed little relationship to outcome variables; caregiver appraisal of increased stressfulness and decreased self-efficacy related to the care receiver's behavior problems was associated with higher levels of depression; use of some types of coping strategies (logical analysis, affect regulation, problem-solving, and information seeking) related to better outcomes; emotional distancing related to higher levels of depression; satisfaction with social network and activities related to increased life satisfaction and health; appraisal accounted for 21% of the variance in depression and 11% of the variance in life satisfaction; coping accounted for 24% of the variance in depression and 15% of the variance in life satisfaction and 22% of the variance in self-rated health | |
| 11. Not reported | 11. Caregivers appraised behavior problems as more stressful than impairment in ADLs and IADLs; they rated their ability to manage behavior problems as lower than their ability to manage ADLa dn IADL impairment | |
| 12. Measured same variables for care receiver as for caregiver | 12. Increased care receiver cognitive impairment associated with increased caregiver depression, decreased emotional and instrumental support from care receiver, and restricted activities outside the home; sleep disturbances in care receiver not related to depression or sleep disturbance for caregiver | 12. No sleep disturbances measured in this sample of care receivers |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Authors | Study Design | Sample Size & Type |
|---|---|---|
| 13. Motenko (1989) | 13. Descriptive correlational | 13. Convenience sample of wife caregivers recruited from local agencies (n=50) |
| 14. Pearson, Verma & Nellett (1988) | 14. Descriptive correlational | 14. Convenience sample of caregivers for consecutive admissions to a geropsychiatric unit (n=56) |
| 15. Pett, Caserta, Hutton, & Lund (1988) | 15. Descriptive correlational | 15. Purposive sample of middle-aged, female, child-rearing caregivers recruited from support group mailing lists of 16 states (n=181) |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Behavior Measure | Mediators of Negative Consequences | Measures of Negative Consequences of Caregiving |
|---|---|---|
| 13. Not measured | 13. (a) general frustration with caregiving: 9-item scale; (b) frustration with specific aspects of caregiving: multi-item scale; (c) general gratification with caregiving: single item; (d) gratification with specific aspects of caregiving: 3-item scale | 13. (a) well-being: Dupey Psychological Index; (b) change in marital closeness: Lopate Emotional Support System Widow's Scale |
| 14. Disruptive behavior: multi-item scale developed by Deimling & Bass (1984) | 14. Not measured | 14. (a) distress: 17-item scale measuring stress from ADL & IADL items; (b) stress: Relatives Stress Scale |
| 15. Not measured | 15. Perceived coping: Jaloweic Coping Scale | 15. (a) burden: Zarit Burden Interview; (b) life satisfaction: LSI-Z; (c) perceived health: single item |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Other Variables Measured | Results | Comments |
|---|---|---|
| 13. ADL function, severity of dementia, duration of dementia, meaning of caregiving | 13. As gratification increased, total well-being increased; as frustration increased, total well-being decreased; change in marital closeness related to gratification in caregiving; amount of supervision needed not related to frustration or gratification | 13. No p values reported for correlations between well-being and frustration and gratification scores; |
| 14. Cognitive status, ADL and IADL impairment | 14. Disruptive behavior more highly correlated with caregiver burden and distress than other care receiver variables | 14. Although they reported that burden related to psychiatric diagnosis, no data was presentedto substantiate that claim |
| 15. Demographic variables, family characteristics, caregiving history, informal social support, relationship to care receiver, ADL impairment, employment status of caregiver, perceptions regarding nursing home placement, percentage of caregiving responsibilities | 15. Higher burden and lower life satisfaction associated with living with care receiver, higher percentage of caregiving responsibilities, lower health, and less satisfaction with social support; employment, demographic variables, care receiver functional status and perceptions regarding nursing home placement not associated with burden or life satisfaction | |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Authors | Study Design | Sample Size & Type |
|---|---|---|
| 16. Poulshock & Deimling (1984) | 16. Descriptive correlational | 16. Purposive, stratified sample of caregivers recruited from 120 referral agencies (n=614) |
| 17. Pratt, Schmall, Wright, & Cleland (1985) | 17. Descriptive correlational | 17. Non-random sample of caregivers from mailing lists of ADRDA support groups and educational lectures (n=240) |
| 18. Pruchno & Resch (1989) | 18. Descriptive correlational | 18. Convenience sample of spouse caregivers from a variety of sources (n=315) |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Behavior Measure | Mediators of Negative Consequences | Measures of Negative Consequences of Caregiving |
|---|---|---|
| 16. 23-item disruptive behavior scale | 16. Burden: 23-item scale measuring the caregiver's interpretation of how upsetting the disturbing behaviors were | 16. (a) negative family relations: 11-item ECF scale; (b) activity restriction: 11-item scale; (c) depression: Zung Depression Scale |
| 17. Not measured | 17. (a) coping: F-Copes, 30-item scale measuring internal and external coping strategies; (b) presence of confidant: single item | 17. (a) burden: Zarit Burden Interview; (b) caregiver health: (information on measure not reported) |
| 18. 34-item scale of confused behaviors and cognitive problems | 18. Not measured | 18. (a) depression: CES-D depression index; (b)global burden: single item rating; (c) burden: 17-item scale from items in the literature |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Other Variables Measured | Results | Comments |
|---|---|---|
| 16. ADL impairment, social function of care receiver, cognitive incapacity | 16. Magnitude of correlations between measured of care receiver impairment and corresponding measured of burden greater than between non-corresponding measures of burden; moderate correlations between impact, burden, and care receiver impairment; measures of impact best explained when burden mediates between impairment and impact | |
| 17. Relationship to care receiver, living arrangements, demographic variables | 17. No significant differences in burden based on caregiver sex, income, education, place of residence or caregiver age; burden not related to presence of confidant or membership in support group; decreased burden related to increased health; burden related to all three internal coping strategies (reframing, confidence in problem-solving, and avoidance response) and to two external coping strategies (spiritual support and extended family) | |
| 18. Severity of care receiver impairment, nature of caregiiving, emotional investment in relationship with care receiver | 18. Wives were more depressed and burdened than husbands; emotional investment correlated with depression and burden for wives and with burden for husbands; while the 7 predictors explained similar amounts of depression for both men (24%) and women (29%), they explained nearly twice as much burden in women (32%) than in men (19%) | |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Authors | Study Design | Sample Size & Type |
|---|---|---|
| 19. Quayhagen & Quayhagen (1988) | 19. Descriptive correlation | 19. Convenience sample of caregivers recruited from the ADRDA (n=58) |
| 20. Rabins, Mace & Lucas (1982) | 20. Descriptive | 20. Convenience sample of caregivers for patients with dementia recruited from a psychiatry department (n=55) |
| 21. Scott, Roberto, & Hutton (1986) | 21. Descriptive | 21. Convenience sample of primary caregivers recruited from the patient pool of one of the authors (n=23) |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Behavior Measure | Mediators of Negative Consequences | Measures of Negative Consequences of Caregiving |
|---|---|---|
| 19. MBPC | 19. (a) coping: modified version of the Coping Strategies Inventory, 48-item scale measuring 6 types of coping; (b) management strategies: 59-item scale measuring stimulation techniques used with the care receiver; (c) social support | 19. (a) life satisfaction: LSI-Z; (b) physical health: 10-point self-anchoring ladder scale |
| 20. Frequency of responses coded for an open-ended question regarding the "biggest problem" in caregiving | 20. Not measured | 20. Frequency of problems cited by caregivers in response to open-ended questions |
| 21. Not measured | 21. (a) coping: 43-item behavior coping indes developed from the literature; (b) family support: data from open-ended questions coded to give scores on total assistance, affective quality of support, and perceived adequacy of support | 21. Burden: Zarit Burden Interview |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Other Variables Measured | Results | Comments |
|---|---|---|
| 19. Relationship to care receiver, respite | 19. Three groups of caregivers were identified (husbands, wives, and daughters), no differences between groups on measures of well-being; there were differences between groups on what they found stressful (e.g., wives upset by doing embarassing things, while daughters expressed difficulty staying home with the care receiver); after controlling for stress, increased well-being for the entire sample was assoicated with decreased use of fantasy, self-blame, and stimulation activities, and increased social support; although the 3 groups tended to identify similar coping and management strategies, they differentially impacted their well-being | |
| 20. Demographic variables | 20. Behavior problems cited as frequent and often serious problems for caregivers; fatigue, anger, depression, family conflict, and restriction of social activities reported by >50% of caregivers | |
| 21. Cognitive functioning of care receiver | 21. One-third of the sample were rated as receiving more than enough support; an additional 47.6% were rated as receiving enough support; greater burden was reported by caregivers rated as not receiving enough support, however, caregivers who reported having more than enough support had the second highest amount of burden; mental status not related to burden; caregivers rates as having enough support were rated as having better caregiving effectiveness than other caregivers | 21. Statistical significance of data not reported |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Authors | Study Design | Sample Size & Type |
|---|---|---|
| 22. Sheenan & Nuttal (1988) | 22. Descriptive correlational | 22. Convenience sample of caregivers recruited from local agencies (n-98) |
| 23. Zarit, Reever, & Bach-Peterson (1980) | 23. Descriptive correlational | 23. Convenience sample of caregivers recruited from a research and training center (n=29) |
| 24. Zarit, Todd, & Zarit (1986) | 24. Longitudinal follow-up two years after initial testing | 24. Convenience sample of spouse caregivers (n=53) |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Behavior Measure | Mediators of Negative Consequences | Measures of Negative Consequences of Caregiving |
|---|---|---|
| 22. MBPC | 22. (a) affection: 9-item scale measuring degree to which care receiver possed certain traits; (b) personal strain: 6-item scale measuring physical, social, & fincial disruption from caregiving; (c) negative emotion: 10-item scale measuring caregiver's negative feelings towards caregiving role | 22. (a) psychological problems: Hopkins Symptom Checklist; (b) personal strain: 6-item scale measuring physical, social & emotional disruption from caregiving |
| 23. MBPC (16 items) | 23. Not measured | 23. Burden: 29-item Zarit Burden Interview |
| 24. MBPC (28 items) | 24. Not measured | 24. (a) burden: Zarit Burden Interview; (b) nursing home placement: open-ended question regarding nursing home placement |

Table 2.1 Quantitative Research on Family Caregiving for Persons with Dementia

| Other Variables Measured | Results | Comments |
|---|---|---|
| 22. Demographic variables, ADL impairment | 22. Increased strain related to ADL impairment, behavior problems, increased care provision, decreased affection, increased distress, and increased conflict; increased negative caregiver emotions related to decreased affection, increased functional impairment, decreased satisfaction, and increased conflict; increased depression related to negative affect, decreased affection, increased conflict, and increase strain; 62% of variance in strain explained by conflict, ADL impairment, living situation & reaction to ADL impairment; 60% of variance in negative emotion explained by conflict, reaction to ADL limitations, and behavior problems | 22. Regression equations used stepwise regression techniques |
| 23. Functional and cognitive impairment, social support, demographic variables, relationship to care receiver, duration of illness, frequency of visits by informal and formal support services | 23. None of the behavior or mental status variables correlated with burden; only frequency of family visits significantly correlated with caregiver burden | 23. Relatively low amount of burden detected in this study |
| 24. Mental status, social support, quality of support, quality of relationship, information regarding placement decsion | 24. Severity of care receiver symptoms not related to caregiver burden or nursing home placement; no difference betweeh husband and wife caregivers in burden or placement outcomes | |

Table 2.2 Qualitative Studies of Caregiving for Persons with Dementia

| Authors | Sample Size & Type | Purpose of Study |
|---|---|---|
| 1. Bodnar, MaloneBeach, Spore, & Zarit (1988) | 1. Convenience sample of caregivers who were providing care in their homes to persons with problem behaviors (sample size not available) | 1. To identify strategies used by caregivers to manage disruptive behaviors |
| 2. Bowers (1987) | 2. Convenience sample of 33 middle aged caregivers caring for aging parents | 2. To describe the purpose of caregiving activities and the stress of inter-generational caregiving |
| 3. Chenoweth & Spencer (1986) | 3. Non-random sample from mailing lists of a state ADRDA (n=289) | 3. To explore the experiences of family caregivers from the time of earliest recognition of symptoms of dementia throughout the course of the illness |

Table 2.2 Qualitative Studies of Caregiving for Persons with Dementia

| **Major Findings** | **Comments** |
|---|---|
| 1. (a) six categories of caregiver strategies were identified (in rank order by frequency): acceptance/avoidance, reasoning, reassurance, stimulation and coercion; (b) rank order of strategies by mean success: avoidance/acceptance, stimulation, reassurance, reasoning, coercion | 1. Relationship between behavior problem, type of strategy, and success unclear (e.g., are certain strategies more successful with certain behaviors?) |
| 2. (a) the work of caring for a person with dementia is largely invisible, directed toward protecting the person's self image and his/her relationship with the caregiver; (b) strategies for protective caregiving include protecting the parent from awareness of the event or its meaning, or changing the meaning or significance of the event | 2. The caregiver's perception that events are threatening for the care receiver influences the strategies she uses to manage those situations |
| 3. (a) episodes of bizarre, unexplainable behaviors lead caregivers to seek a diagnosis of dementia; (b) early in the dementia, caregivers felt anger and guilt when attempts to assist care receiver were resisted; (c) many reported difficulty understanding that the behavior and personality changes were related to the dementia; (d) the most difficult problem for caregivers was the need for constant supervision so the care receiver would not get hurt | 3. The development of the caregiver's recognition and understanding of how the dementia is manifest mirrors the gradual and insidious development of the disease itself; gradually, most caregiver realize the behaviors are related to the dementia |

Table 2.2 Qualitative Studies of Caregiving for Persons with Dementia

| **Authors** | **Sample Size & Type** | **Purpose of Study** |
|---|---|---|
| 4. Schneider & Garron (1980) | 4. Convenience sample of spouse caregivers for someone with dementia (n=30) | 4. To explore the kinds of symptoms and behaviors that were particularly stressful for family members to manage at home |
| 5. Shomaker (1986) | 5. Convenience sample of 18 persons with dementia and their caregivers, and various health care providers involved in the person's care | 5. To determine whether there was a connection between the care receiver's behavior prior to the onset of dementia and abnormal behavior associated with dementia |
| 6. Wilson (1989) | 6. Purposive sample of primary caregivers for persons with dementia (n=20) | 6. To explore and describe the process of family caregiving for elderly relatives with dementia |

Table 2.2 Qualitative Studies of Caregiving for Persons with Dementia

| **Major Findings** | **Comments** |
|---|---|
| 4. (a) caregivers expressed great uncertainty regarding how to manage the care receiver's aberrant behaviors and declining self-care ability; (b) should they push the care receiver to be as independent as possible, or be protective and directive to avoid confrontations? (c) all caregivers had difficulty accepting and recognizing the severity of the care receiver's impairment; (d) caregivers reported fewer affective and social symptoms of the care receiver than cognitive symptoms | 4. Unclear whether cognitive symptoms included behavioral manifestations |
| 5. (a) initially, caregivers denied there was any continuity of behavior; (b) later, habits valued by the care receiver in the past were reported to be occurring in the present in fragmented form; (c) reinterpretation of the care receiver's behavior as related to previous behavior was comforting for caregivers | 5. The researcher contaminated the findings by using the attribution of meaning as a tool to explore the behavior with caregivers. Still, the results suggest that the caregivers who are able to find meaning in the behavior find the behavior less problematic than when they were unable to attribute any meaning to the behavior. |
| 6. (a) caregivers are confronted with many negative choices; (b) the uncertainty and unpredictability of the situation are difficult for caregivers to cope with; (c) different coping strategies are used by caregivers to buffer the difficulties of caregiving | 6. The findings describe how caregivers cope with the demands of the caregiving situation in a general way. No discussion of how caregivers cope with problems related to the care receiver's impairment or behavior problems. |

Table 2.3 Variables Measured in Caregiver Research

| Authors | Situation Variables | | Care Receiver Variables | | | | | Caregiver Variables | | Interpersonal Mediators | | Intrapersonal Mediators | | | Negative Consequences of Caregiving | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Relationship to Care Receiver | Living Situation | Demographic Variables | Mental Status | Behavior Problems | ADL/IADL Impairment | Social Function | Demographic Variables | Employment Status | Social Support | Quality of Relationship | Appraisals or Attributions | Coping Styles or Strategies | Other Mediators | Mental Health | Physical Health | Lifestyle Changes | Well-Being Indicators | Change in Family Relationships |
| Baillie, Norbeck & Barnes (1989) | | | X | | | | | X | | X | | X | | | X | | | | |
| Cohen & Eisdorfer (1988) | | X | X | | | | | X | | | | X | | | X | | | | |
| Coppel, Burton, Becker & Fiore (1985) | | | | | X | | | | | | | X | | | X | | | | |
| Deimling & Bass (1986) | | | | X | X | X | X | | | | | | | | X | | X | | X |
| Fitting, Rabins, Lucas & Eastham (1986) | | | | | | X | | | | X | X | | | | X | | | | X |
| George & Gwyther (1986) | X | X | | X | X | | | | | X | | | | | X | X | X | X | |
| Gilhooly (1984) | | | | X | X | X | | | | X | X | | | | X | | | X | |
| Gilleard, Belford Gilleard, Whittick & Gledhill (1984) | | | | | X | | | | | X | X | | | | X | | | | |

## Table 2.3 Variables Measured in Caregiver Research

| Authors | Situation Variables | | Care Receiver Variables | | | | | Caregiver Variables | | Interpersonal Mediators | | Intrapersonal Mediators | | | Negative Consequences of Caregiving | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Relationship to Care Receiver | Living Situation | Demographic Variables | Mental Status | Behavior Problems | ADL/IADL Impairment | Social Function | Demographic Variables | Employment Status | Social Support | Quality of Relationship | Appraisals or Attributions | Coping Styles or Strategies | Other Mediators | Mental Health | Physical Health | Lifestyle Changes | Well-Being Indicators | Change in Family Relationships |
| Haley, Pardo & Eastman (1988) | | | | X | X | X | | | | | | X | X | | X | X | | X | X |
| Haley, Levine, Brown & Bartolucci (1987) | | | X | X | X | X | | X | | X | | X | X | | X | X | | X | |
| Haley, Brown, & Levine (1987) | | | | | X | | | | | X | | X | X | | | | | | |
| Moritz, Kasl & Berkman (1989) | | | | | | | | | | | | | | | X | X | X | | X |
| Motenko (1989) | | | | X | | X | | | | | | X | | X | | | | X | X |
| Pearson, Verma & Nellett (1988) | | | | X | X | X | | | | | | | | | X | | | | X |
| Pett, Caserta, Hutton & Lund (1988) | | | X | | | X | | X | X | X | | | X | | X | X | | X | |
| Poulshock & Deimling (1984) | | | | X | X | X | X | | | | | | | X | X | | X | | X |

## Table 2.3 Variables Measured in Caregiver Research

|  | Situation Variables |  | Care Receiver Variables |  |  |  |  | Caregiver Variables |  | Interpersonal Mediators |  | Intrapersonal Mediators |  |  | Negative Consequences of Caregiving |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Authors | Relationship to Care Receiver | Living Situation | Demographic Variables | Mental Status | Behavior Problems | ADL/IADL Impairment | Social Function | Demographic Variables | Employment Status | Social Support | Quality of Relationship | Appraisals or Attributions | Coping Styles or Strategies | Other Mediators | Mental Health | Physical Health | Lifestyle Changes | Well-Being Indicators | Change in Family Relationships |
| Pratt, Schmall, Wright & Cleland (1985) | X | X | X |  |  |  |  | X |  | X |  |  | X |  | X | X |  |  |  |
| Pruchno & Resch (1989) |  |  |  | X | X |  |  |  |  |  | X |  |  |  | X |  |  |  |  |
| Quayhagen & Quayhagen (1988) |  |  |  |  | X |  |  |  |  | X |  |  | X | X |  | X |  | X |  |
| Rabins, Mace & Lucas (1980) | X |  | X |  | X |  |  | X |  |  |  |  |  |  | X | X |  | X |  |
| Scott, Roberto & Hutton (1986) |  |  |  | X |  |  |  |  |  | X |  |  | X |  | X |  |  |  |  |
| Sheenan & Nuttall (1988) |  |  | X |  | X | X |  | X |  |  | X | X |  | X | X | X | X |  | X |
| Zarit, Reever & Bach-Peterson (1980) | X |  |  | X | X | X |  |  |  | X |  |  |  |  | X |  |  |  |  |
| Zarit, Todd & Zarit (1986) |  |  |  | X | X |  |  |  |  | X | X |  |  |  | X |  |  |  |  |

# Chapter 3: Method

## Sample

In this study, purposive sampling was used to identify family caregivers for persons with Multi-infarct dementia, Possible/Probable Alzheimer's Disease, and/or mixed dementia. In particular, caregivers for persons recently diagnosed with dementia, who were still in the early stages of the disease and/or who were actively managing potentially problematic behaviors of the care receiver were sought. The sample was drawn from an outpatient clinic that specializes in the diagnosis of dementia. The clinic is located in a major metropolitan area in the Northwest and serves clients from both that area and remote communities in this largely rural state. Potential subjects were identified by a nurse practitioner in the clinic and by a review of the clinic charts.

Eligible persons were contacted in clinic when possible or, if necessary, by phone to determine interest in participating in the study. A total of 84 charts were reviewed. Of those, 22 met the inclusion and exclusion criteria. Reasons for ineligibility included no family caregiver, recent nursing home placement, or no diagnosis of dementia made. Of the 22 eligible patients, six caregivers refused to participate, six lived prohibitively far from the researcher's home, and ten consented to participate.

Three caregivers refused to participate because they were too busy with caregiving and other obligations. Three caregivers refused to participate because they believed that the care receiver did not have problems with his/her memory, or that s/he was "not that bad yet". This belief was contrary to chart data that indicated severe enough cognitive impairment to warrant a diagnosis of Possible or Probable Alzheimer's Disease.

The sample consisted of 10 white, female caregivers who ranged in age from 51 to 80. Nine of the caregivers were married, one was widowed. Eight of the caregivers were spouses caring for their husbands, two were adult daughters caring for their mothers. All of the care receivers were white, lived with the caregiver, and ranged in age from 67 to 86. All of the caregivers in this sample completed high school and five had additional post-high school training or college. Approximately one third of the care receivers had less than a high school education, one third completed high school, and one third had at least some college education. Median income for the caregivers fell in the $15,000 to $24,900 range, with two caregivers reporting annual incomes of less than $6,000. Eight of the care receivers shared income with the caregivers. The other two were reported to have incomes in the $3,000 to $5,900 and $10,000 to $14,900 ranges.

## Procedure

### Data Collection

Data were collected during face-to-face interviews in the home of the caregiver using a semi-structured interview guide. Each caregiver was interviewed once. The interviews lasted from 45 minutes to 1.5 hours and were tape-recorded.

### Instruments

A semi-structured interview guide was used during the interviews. During the course of data collection and analysis, additional questions were added to the interview guide. In addition, demographic data on both the caregiver and the care receiver were obtained (Appendix A).

### Data Analysis

The tapes were transcribed and reviewed for accuracy. The transcriptions served as the raw data used in analysis. In addition, theoretical and methodological notes were generated following each interview to record initial reactions and hypotheses regarding the caregiver's management of potentially problematic situations involving the care receiver. The theoretical notes were used to explore ideas about the caregiver's effectiveness in managing problems, to compare and contrast the caregiver's management of different problems, and to look at similarities and differences between caregivers. The methodological notes were used to evaluate the semi-structured interview guide. Planned changes in data collection strategies were recorded in the methodological notes.

The analysis of these data was a complex and involved process. However, it essentially involved four different, yet overlapping phases.

_Phase one_. During phase one concepts thought to be central to the caregiver's management of potentially problematic situations were identified. In order to identify the concepts the transcripts were read repeatedly and significant passages of text highlighted. Theoretical notes were generated to identify important themes and emerging concepts. A list of initial codes that reflected major themes was then developed and the transcripts were coded according to that list. The coded data for each concept were then collated.

_Phase two_. Phase two involved concept development. In general, this phase involved linking the developing theoretical notions with actual data in order to support or refute those ideas. During this phase the data for each concept were examined in order to develop definitions for each concept and identify different dimensions of the concepts. Again, theoretical notes regarding possible definitions and dimensions of the concepts were generated.

_Phase three_. During phase three, relationships between concepts were explored and refined. This process involved examining different situations described by the caregivers in terms of the emerging concepts. Hypotheses regarding the nature of the relationships between concepts were examined for their applicability across situations and across caregivers in the sample. Based on this analysis, a tentative model explaining differences in effectiveness in the caregivers' management of problem situations was developed.

Phase four. During the final phase, evidence for construct validity was gathered in three ways. First, three caregivers were asked to participate in validation interviews. These caregivers were interviewed in much the same manner as the others in the sample. In addition, I presented my interpretation of the factors that influenced their management and asked if that was consistent with their experience. These caregivers were enthusiastic in support of my interpretation of factors that influenced how they managed problem situations. Their responses were used to further refine the model.

Second, a draft of the conceptual definitions and model was presented at a seminar that focuses on research issues in gerontological nursing. The seminar is attended by faculty and doctoral students who are experts in the field of gerontological nursing. Earlier, participants in the seminar had been given the transcripts from two different interviews. In general, the seminar participants validated the model and definitions. Additional comments and criticisms were incorporated into subsequent drafts of this paper.

Finally, two expert nurse practitioners who work with families of patients with dementia were asked to review a draft of the results section in order to determine how well it fits with their understanding of caregiver management of potentially problematic situations. They also expressed support for the model's ability to describe the effectiveness with which caregivers manage potentially problematic situations involving the care receiver.

It is important to note that although these four phases are described separately, they overlapped a great deal. This analysis involved constant movement between the theoretical notes and the data. As a general rule, when my thinking became too confused or convoluted, I went back to the data to refocus. I strived to reach a balance between the, at times, overwhelming complexity involved in managing dementia-related problems and an over-simplification of the process. The results of the analysis are presented in the next chapter.

# Chapter 4: Results

The purposes of this study were to identify and define the variables central to a caregiver's management of potentially problematic situations involving the care receiver with dementia and to develop a model that might explain the differences in how effectively those situations were managed. Initially, it was thought that understanding the caregiver's appraisal of specific episodes of problematic behavior was central to an explanation of how effectively she managed the behavior. However, very early in this study it became apparent that caregivers found it difficult to describe specific episodes of care receiver behavior. The following exchange typifies the unsuccessful attempts I encountered trying to get the caregiver to focus on a single episode of the problem behavior:

INTERVIEWER: I'm wondering if you could tell me of a specific instance when he has accused you of taking his wallet?
RESPONDENT: Well, it's been happening a lot lately. The last few weeks it has been really bad, every night.
INTERVIEWER: Has he accused you of something in this past week? Or today?
RESPONDENT: Well, it's been every night for the last week or two, it's been really bad.
INTERVIEWER: Can you tell me about one time when that happened recently?
RESPONDENT: Well, every night.
INTERVIEWER: It happened last night?
RESPONDENT: No, I think I finally reached him last night because over the weekend I gave him such a bad time about it I think I scared him.
INTERVIEWER: Tell me about what happened over the weekend.

RESPONDENT: Well, this, I don't know, Thursday or Friday when he was back on this business again about my taking a box out of his onion shed. And he'll keep repeating the same thing instead of forgetting it. Like I think, oh well, he'll forget it. And I'm sure it's just this paranoia because I never did take any out.

INTERVIEWER: So on Thursday night...

RESPONDENT: So then, he'll start in, he'll just start in on that at night or almost anytime on that, but then he started a few weeks ago, he started carrying his billfold to bed...

Despite persistent probing, this caregiver continued to describe the behavior in more general terms.

The other caregivers in the sample had similar difficulties when asked to describe specific episodes of the problem behavior. Instead, they described the behavior in more aggregated terms (e.g., "he's always losing things", "every time we passed the bank he wanted to stop in", "he watches the mailbox", "she gets up in the morning and she says the same things over and over", he just looks at me so terrible and starts accusing me", he goes in the wrong direction, looks in the wrong cupboard"). The exception to this pattern of reporting problem behaviors was observed when the episode was, in and of itself, quite stressful for the caregiver. For example, one caregiver described how the care receiver was lost for 45 minutes when she went to the doctor's office. This episode was very distressing to her and she recalled it easily, with minimal prompting.

This finding suggests two things. First, an interview format may not be the best way to obtain information about a caregiver's appraisal of specific episodes of problem behavior. Participant observation techniques may be needed to get at that information. Second, and perhaps more importantly, isolated episodes of certain care receiver behaviors may not, in and of themselves, be very stressful for the caregiver to manage. Instead, the stress seems to come from the need to manage the behavior repeatedly. That may explain why caregivers were able to describe the behaviors in aggregate.

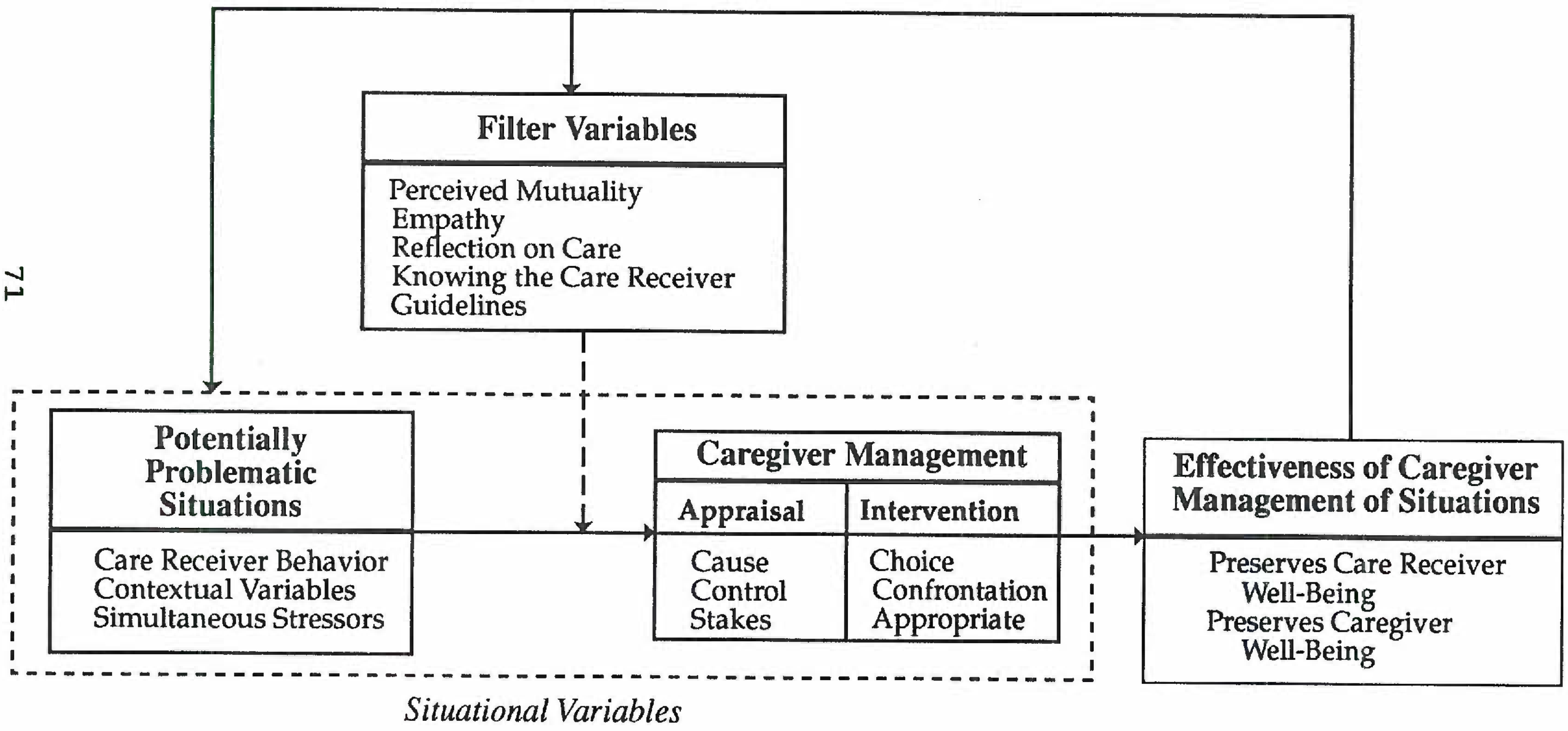
It is also important to note that initially I planned to study the care receiver's "potentially problematic behaviors" because this is a significant source of stress for caregivers. Indeed, the caregivers in this sample reported that many of the problems they managed involved the care receiver's behavior. However, some caregivers framed their descriptions of the problem in terms of problematic situations involving the care receiver. In order to be more inclusive, the term "potentially problematic behaviors" was renamed "potentially problematic situations". The focus of this study then became the caregiver's appraisal of potentially problematic situations. In addition, other concepts were identified that seem to be central to an understanding of caregiver management of potentially problematic situations involving the care receiver. These concepts are described in the following sections.

## Conceptual Model

A conceptual model that explains why some caregivers manage potentially problematic situations involving the care receiver with dementia more effectively than other caregivers is presented in Figure 4.1. In this study, effectiveness is defined as the extent to which the caregiver is able to avoid, prevent, resolve, endure or contain the situation while preserving or enhancing the care receiver's and her own well-being.

This model suggests that the caregiver's effectiveness in managing potentially problematic situations involving the care receiver was mediated by two sets of variables, situational variables and filter variables. Included in the situational variables are the potentially problematic situation, the caregiver's appraisal of the situation, and the interventions she used to manage the situation. The filter variables are those less transient variables that characterize the caregiver's general approach to caregiving. The filter variables include the caregiver's perceived mutuality, empathy, reflection on care, knowledge of the care receiver, and guidelines for care. In addition, the author acknowledges that other variables influenced the caregiver's management of potentially problematic situations (e.g., the care receiver's level of cognitive impairment,

Figure 4.1 Conceptual Model of Caregiver Management of Potentially Problematic Situations Involving the Care Receiver with Dementia



duration of caregiving, social support, etc.). However, because this study focused primarily on the caregiver and situational variables that influenced management of potentially problematic situations, those other variables have been excluded from the model.

In essence, the data suggest that caregivers approached each potentially problematic situation with an interpretive framework, or "filter" through which they perceived the situation. This filter represents the set of expectations and assumptions the caregiver has of the care receiver based on her past and present relationship with the care receiver, her previous life experiences, and her current life situation. This filter influenced the caregiver's appraisal of the potentially problematic situation, her efforts to manage the situation, and how effectively she intervened. This filter was, in turn, influenced by repeated management of potentially problematic situations.

In the next sections I will define each of the major concepts in the model and provide excerpts from the interview text as exemplars. I will also discuss some of the hypothesized relationships among these concepts. Finally, I will present several problematic situations from the data to illustrate how the model can be used to understand the factors that influenced caregiver management of different situations.

## Potentially Problematic Situations

Potentially problematic situations are defined as those situations, which arise in the context of caring for someone with dementia, that may threaten the well-being of the care receiver and/or the caregiver and that must be managed by the caregiver. These potentially problematic situations may involve: (1) behavior by the care receiver that is typically associated with dementia (e.g., wandering, perseverative questions), (2) functional disabilities related to the dementia (e.g., lapses in hygiene, problems managing money), or (3) situational circumstances that affected the care receiver adversely (e.g., social interactions that increase agitation or disorientation).

These data suggest that it was important to understand not only the care receiver's behavior, but also the context in which it occured. Behaviors that were problematic in one setting might not have been perceived as such in another. Contextual factors that influenced the care receiver's behavior influenced how effectively the caregiver managed the situation. For example, one caregiver reported:

> If I have a bad day with my son, I am less tolerable of my mother. That's understandable. But on a good day, you know, as the family is running smooth and stuff, then she's not a problem.

It is important to note that the situations are defined as _potentially_ problematic. This stems from the finding in this and previous research that caregivers did not always agree in their perception of what was problematic. Instead, the perception that a situation was or was not problematic was influenced by the filter through which the caregiver perceived the behavior, as well as her appraisal of the cause of the behavior, what was at stake in the situation, and the care receiver's ability to control his/her behavior. The nature of the relationships among these variables will be discussed in more detail in a later section.

## Appraisal

The caregiver's appraisal of potentially problematic situations involves three dimensions: (1) appraisal of the cause of the behavior; (2) appraisal of the care receiver's volition or control over the behavior; and (3) appraisal of what is at stake in the situation. Each of these dimensions will be addressed separately.

### Appraisal of Causality

The caregiver's appraisal of causality is defined as her perception of why the behavior occurs or her attribution of what causes or triggers it. Appraisal of causality can be divided into six different categories: (1) dementia-related; (2) current situational circumstances (3) underlying needs or emotions; (4) historical event; (5) mitigating circumstances; or, (6) unknown reasons.

It is important to note that the caregivers frequently attributed the care receiver's behavior to more than one cause. For example, several caregivers perceived that the dementia made the care receiver vulnerable to different situational demands. Sometimes, the caregiver had several explanations for the same behavior. For purposes of clarity, the different attributions of causality will be described separately.

Dementia-related behavior. Many of the caregivers reported that the care receiver's behavior was caused by or was a symptom of his/her dementia. For some caregivers, the explanation was very simple. For example, one caregiver explained that her mother colored her hair all of the time because "she forgets she's done it". Other caregivers provided a more elaborate explanation of how the dementia causes the care receiver's behavior:

> He cannot put the association of "an extension cord is a tool so it would be where the tools are". He is truly confused, like he's hearing it for the first time, but he's not sure what it is he's hearing. He might not associated the need for the extension cord with the extension cord. He'll puzzle "if I don't know why I'm going to use this, what is it that I'm looking for?"

In general, caregivers who appraised the cause of the care receiver's behavior to be related to dementia were less likely to perceive that the care receiver was able to control the behavior. It is interesting to note that the caregivers in this sample reported many behaviors that they did not attribute directly to the care receiver's dementia. When asked specifically about the role of dementia, they conceded that the behavior would probably not occur if the care receiver were not demented. However, the dementia explanation seemed secondary to the other explanations offered by the caregivers. These alternative explanations are described below.

Current situational circumstances. Some caregivers stated that the care receiver's behavior was a response to certain situational or environmental stimuli. In some cases the caregiver identified specific triggers they believed caused the behavior. For example, one caregiver reported:

> She read an article in the paper where they caught this, these people that were stealing checks out of the mailboxes. It was in the paper about a week and a half ago...She read that article, so lo and behold, every day I hear this "you be sure and get my checks before they come so they don't steal them out of the mailbox".

Other caregivers could not identify specific triggers, but knew that certain situations were more or less likely to result in problematic situations involving the care receiver.

> I always dread the weekend coming. For some reason it's always worse. During the week it's not so bad, but the weekend is a catastrophe because on the weekends Mother seems to act the worst.
>
> If we go to the Rock Club or someplace where we have to sit for long periods, that's hard on him.

In some situations, the caregiver attributed the care receiver's behavior to the interactional style of others.

> The nurses would get very angry and defiant with him and then he, he would respond to them in (the same way).

Underlying needs or emotions. Sometimes the caregiver reported that the care receiver's behavior represented some underlying emotional or physical need or that it had some symbolic meaning. For example, one caregiver explained that her husband hid his tape measures because they are "just something that he uses, meaning everything he owns". She went on to explain:

> He's trying to hang on. I know cause he, it's the only way he can feel like he's still hanging onto something. Because it's (the dementia) taken away his care and he's had to give up his farming and his machinery and it's just that so many things have been taken away and I thing he is just clinging to it because that's what's left.

In some cases the appraisal that the care receiver's behavior represents some underlying need facilitated the caregiver's choice of intervention strategy. Interventions that addressed the care receiver's underlying needs were generally more effective than interventions that were directed at the behavior alone. For example, one caregiver reported that her husband asked her repeatedly about their bank accounts and nagged her frequently about wanting to check the balance. She perceived that he did this because he was worried and intervened by allowing him to check the balance and by reassuring him that the account was intact.

In other situations, the appraisal that the care receiver's behavior reflected some underlying need did not facilitate effective management of the behavior. In situations where the caregiver believed that the underlying need was in opposition to her own well-being she was less likely to manage the behavior effectively. For example, one caregiver described how her mother:

> "cries and cries and cries and she starts in with this 'forgive me' and she starts crying and crying and crying, she'll just cry and cry and cry".

When asked why her mother was crying, the caregiver replied "she's just, I think, basically feeling sorry for herself in a large way and wants and wanting, I don't know, maybe more attention, more love". In this situation, the caregiver already felt as if she was giving more than she had to give. Consequently, her perception that her mother's behavior meant she needed more attention resulted in increased stress for the caregiver.

Historical event. Sometimes the caregiver attributed the care receiver's behavior to an event that occurred in the past. Usually this was a significant event that left a lasting impression on the care receiver. For example, one woman explained that her husband's paranoia regarding money was due, in part, to a gambling loss he sustained in high school. Another caregiver reported that her mother's calling out at night stemmed from her experience with the war as a young adult. In both of these situations, the appraisal that the behavior was caused by events in the past seemed to stymie effective management of the behavior by the caregiver. Because they were unable to change the fact that this had happened, they were frustrated in their attempts to intervene. Their inability to identify situational triggers for the behavior seemed to leave them with no direction for intervention.

Mitigating circumstances. Some caregivers attributed the care receiver's behavior to mitigating circumstances, thereby diminishing the implications of the behavior. These attributions often took the form of attempts by the caregiver to explain how the behavior could have happened to anyone, was an isolated event, or was just not a big deal. For example, one caregiver went to great lengths to blame the difficulty her husband (a skilled mechanic for many years) had constructing bunk beds.

> There again, looking at a badly drawn picture that appeared to have several holes in the bracket and building the bracket so that they just clamped over the upper rails and the lower rails for the ladder. He'd look at the picture instead of thinking of how it was going to be on the rail because it only showed just a side view... actually, it was a combination of two views which he had not realized.

After the interview, the caregiver insisted that I accompany her to her husband's workshop so she could show me how confusing the picture was.

Attributing the care receiver's behavior to mitigating circumstances was seen most often in the very early stages of dementia. The caregiver's need to attribute the behavior to causes other than dementia may have reflected her reluctance to accept the implications of the behavior, have been a way for her to protect the care receiver from the stigma of having dementia, or simply been a function of the sporadic nature of early dementia when it is difficult to see a pattern of cognitive impairment.

Some caregivers were able to describe how, in the beginning, they had attributed the care receiver's behavior to certain mitigating circumstances, but that now, in retrospect, they could see that it was the dementia. For example, when trying to explain why her mother was making long-distance phone calls in the middle of the day, one caregiver stated:

> At that time, I didn't know what was going on. I thought maybe she was lonesome or something, but that wasn't the case.

<u>Unknown reasons</u>. Sometimes the caregiver was unable to say why certain behaviors occurred. She tried hard to come up with reasons, but could not settle on a satisfactory explanation for the behavior. For example, one woman continued to search for an explanation of why, four years ago, her mother thought people were coming into her home and steal things.

> I don't know where that ever came from. I have no idea. She lived in a very secure building. I don't know where the theft thing came in. I really don't.

It is as if the dementia alone could not explain why the behavior occurred. Instead, the caregiver assumed there must be some other explanation, something that triggered the behavior. Although this intense search for precipitating factors sometimes helped the caregiver to manage the behavior more effectively (e.g., by avoiding those situations), situations where identification of the triggering factor was elusive increased the caregiver's frustration.

### Appraisal of Care Receiver Control Over Behavior

The caregiver's appraisal of the care receiver's ability to control his/her behavior is defined as the caregiver's perception of whether the care receiver's behavior was volitional and/or whether s/he is able to control the behavior or act differently in the situation. Some caregivers perceived that the care receiver was able to control the behavior or that they acted deliberately. For example, one caregiver described how her mother would act differently when in different situations. When asked to explain why she thought that was, she replied:

> I don't know, I just can't figure out whether she really has this condition (dementia) or whether it's simply her way of wanting things the way she wants them or whatever.

In contrast, other caregivers believed the care receiver could not help the way s/he behaved. For example, when asked to explain why her husband told her the same stories over and over, one caregiver stated:

> You truly know that he does not remember telling you that in the first place.

The more the caregiver perceived that the care receiver could control the behavior, the more likely she was to perceive the situation to be problematic and the less effectively she managed the situation. In contrast, the more the caregiver perceived that the care receiver could not help the behavior, the less problematic the behavior was perceived to be and the more effective her management of the situation.

The caregiver's perception of the care receiver's control seemed to depend, in part, on her attribution of causality. As stated earlier, the caregiver's appraisal that the behavior was due to the care receiver's dementia was related to her perception that s/he was not able to control it.

### Appraisal of Stakes

The caregiver's appraisal of stakes is defined as her perception of how the situation impacts the care receiver's and her own well-being. More specifically, these stakes can be divided into two separate categories: concern for the care receiver's physical, emotional, or financial well-being, and concern for the caregiver's physical, emotional, or financial well-being. Some caregivers perceived the care receiver's behavior as a threat to their own well-being. In describing her mother's requests for increased attention, one caregiver reported:

> I am pretty much already (in constant attendance), but I can't give more than that, I just kind of need my own space, I need a life of my own too. I cannot continuously play nursemaid to mother. You feel that you have absolutely no life of your own. I mean, you can't go anywhere and feel relaxed. You come back earlier (than you planned).

Other caregivers perceived the potentially problematic situation primarily in terms of their concern for the care receiver's well-being. For example, one caregiver described how her husband would get lost when driving in town. She went on to say:

> And then he gets all uptight because he can't go on the wrong way down the one-way street. And this causes stress for him, which upsets him.

It is important to note that these concerns were not necessarily in opposition. In fact, the greater the mutuality, the more the caregiver's concerns for the care receiver's and her own well-being seemed to overlap. For example, one caregiver reported an incident where her husband was ridiculed by others when he mistakenly went into the ladies rest room. She stated that she felt badly for him because she knew it embarrassed him.

In addition, the more the caregiver's needs were met, the less likely she was to perceive the care receiver's behavior was a threat to her own well-being. However, in situations that were highly stressful, where the caregiver's well-being was already compromised, she was more likely to perceive that the care receiver's behavior was a further threat to her own well-being. For example, one caregiver who is in a particularly stressful situation with few resources reported that her mother's calling out in the night was, in part, "her way of getting what she wants".

This behavior interfered with the caregiver's well-being almost nightly:

> And then you know, I am awake also. Even though you lay down it is impossible to sleep, first of all you get yourself too worked up and you can't you can't relax, you know, even if you want to. So and a good thing you know, I don't have to work today, but when this, these kind of nights happen on a workday well, it makes it pretty awful because you are really tired to begin with.

In situations where the caregiver's concern for her own well-being seemed to supersede her concern for the care receiver's well-being she seemed to act less effectively. For example, in the situation above, the caregiver described a night when she tried to tie her mother's door shut with a string to prevent her from wandering around at night. This only served to escalate her mothers agitation, making the situation worse. In contrast, one caregiver described how her concern for her husband's well-being guided her interventions in different problematic situations:

> So rather than to embarrass him or to put something upon him that seems difficult, I just take his clothes and lay them on the bed and don't say anything.

### Summary of Appraisal

In summary, the caregivers in this sample attributed the care receiver's behavior to a variety of causes. In some situations, the behavior was seen to be the result of a combination of factors. For some caregivers, their appraisal helped to diminish their perception of how stressful the situations involving the care receiver were by seeing the behavior as out of the care receiver's control, or by increasing their concern for the care receiver's well-being. For others, their appraisal of the care receiver's behavior helped them to select an effective coping strategy to manage the situation.

In contrast, the appraisals made in other situations tended to compound the problems, either by perceiving the situation to be under the care receiver's control, or by influencing a poor choice of intervention strategy. In later sections, the filter variables that seemed to influence the appraisals made by caregivers in different situations will be discussed.

## Caregiver Interventions

Analysis of these data revealed eleven different types of intervention strategies used by caregivers to manage potentially problematic situations involving the care receiver: (1) monitoring, (2) going along, (3) diversion, (4) putting off, (5) convincing, (6) guiding, (7) fixing/doing for, (8) environmental management, (9) medical management, (10) help-seeking, and (11) caregiver self-care. The definitions for each of these strategies are listed in Table 4.1, along with examples of the strategy from the data. It is important to note that the effectiveness of the caregiver's intervention did not depend entirely on which strategy she used. Instead, the way in which the intervention was implemented and the fit of the strategy

**Table 4.1 Caregiver Interventions and Definitions**

| Intervention Strategy | Definition | Examples |
|---|---|---|
| 1. Monitoring | 1. The type of intervention where the caregiver watches the care receiver in order to detect situations where she might need to intervene in a more active way. | 1. I come home at noon and check on her.<br>I'll kind of keep an eye on him.<br>He'll invite someone to the house in a conversation and, okay, now I'm going to have to hear this so I can remember to follow through for him. |
| 2. Going Along | 2. The type of interventions where the caregiver goes along with what the care receiver is doing or saying and does not try to intervene to change the behavior. | 2. I don't say anything. For instance, he had some jelly to put on his toast and he'd put it on top of his cereal. I just ignore it cause what difference does it make.<br>You keep answering (the repetitive questions) and go on.<br>One time I had an extra billfold and I just took it and put some money in it and gave it to him (when he lost his wallet). |
| 3. Diversions | 3. The type of intervention where the caregiver acts to divert the care receiver's attention, either by changing the topic of conversation, or by engaging the care receiver in alternative activities. | 3. I have deliberately left them (fallen branches) because I figured that would be something he would do on his next bad day.<br>So I try everyday to go out, maybe for a nice drive someplace or go down to the stock market with him just to punch the buttons and see what the stocks are doing.<br>Oh, I just kind of change the subject and talk about other things. |

**Table 4.1 Caregiver Interventions and Definitions**

| Intervention Strategy | Definition | Examples |
|---|---|---|
| 4. Putting Off | 4. The type of intervention where the caregiver will attempt to delay the care receiver by saying that the activity will occur at a later (possible more appropriate) time/date. | 4. I just tell him he has to wait.<br>I said, "Well, mom, when we need the money we'll use it".<br>I tell him, "Well, we'll go down a little later". |
| 5. Convincing | 5. The type of intervention where the caregiver attempts to change what the care receiver thinks, feels, or believes; this can range from comforting reassurance to explanations to more aggressive contradiction, corrections or confrontations. | 5. I picked up the paper and I said, "Look, M., see what it says, it's not you, it's not you, it's this Alzheimer's guy up here" and I'll touch his head.<br>When she mentions her home town I say, "Mom, you can't be alone anymore".<br>I will get up and put her back to bed and say, "Mother, it isn't time, go to bed now, I need some sleep". |
| 6. Guiding | 6. The type of intervention where the caregiver provides information or direction to the care receiver in order to help him/her with something s/he is unable to do independently; this can range from the provision of subtle cues to the provision of information or direction to overt commands to the care receiver. | 6. I have to put his clothing out for him; I just take his clothes and lay them on the bed and don't say anything.<br>I might tell him, "Well, our property taxes are due" something like that.<br>I've worked and worked and worked with him. I've got a little chest of drawers in there, two little drawers is his. I say, "M. this is yours, and you put it (the wallet) in here at night". |

## Table 4.1 Caregiver Interventions and Definitions

| Intervention Strategy | Definition | Examples |
|---|---|---|
| 7. Fixing/Doing For | 7. The type of intervention where the caregiver steps in and remedies the problem situation; this includes assistance with IADLs and ADLs or other situations in need of remedy. | 7. I spend most of my lunch hour racing around here cleaning the place up before it's time to go again.<br>I go and look for it (the lost wallet)<br>If I see he's just not making it, then I'll step in and say, "Well, let's see if we can find it" and then we go together and find it. |
| 8. Environment Management | 8. The type of intervention where the caregiver directs her efforts at things outside the care receiver; this includes management of the physical environment, management of interpersonal interactions between the care receiver and others, and management of the care receiver's identity. | 8. One evening I had to run to school to get my son. There was nobody here with her...I turned the 240 (the power to the stove) off downstairs when I left.<br>I've fixed it so he can hang thing up and the order is better in his workshop.<br>I talked to the girls there (at the bank) because they realized there was something the matter. |
| 9. Medical Management | 9. The type of intervention where the caregiver manages some medical aspects of the care receiver's care in order to manage potentially problematic situations (e.g., medication management). | 9. I gave her the Benadryl syrup at night (to help her sleep through).<br>(There was not a lot of data for this category, but conceptually it seemed important to include.) |

### Table 4.1 Caregiver Interventions and Definitions

| Intervention Strategy | Definition | Examples |
|---|---|---|
| 10. Help-Seeking | 10. The type of interventions where the caregiver seeks outside resources in order to assist her in managing potentially problematic situations; this includes informational, informal and formal resources. | 10. I've been going to these care groups.<br>I finally asked a friend of his if he wouldn't take him to lunch and spend the afternoon with him.<br>When we first went in to have his memory checked, we got some literature on Alzheimer's. |
| 11. Caregiver Self-Care | 11. The type of intervention directed at making the caregiver feel better, not at changing the problematic situation per se. | 11. If I have a bad day and it's really getting to me, I'll say, "Mom, I'm going in my bedroom and watch a movie I want to see."<br>I have found things that are an outlet for me and one of the things is writing...or I get out my crafts and get busy.<br>So I just left her, left the door tight and turned the radio on downstairs so I wouldn't hear all of it. |

with other situational factors were important determinants of how effective the strategy was in managing the situation.

In general, interventions that were subtle, indirect, or non-confrontational were more effective than the more overt, direct, or confrontational strategies. For example, several caregivers described how they guided the care receiver through various activities. However, the manner in which they provided the care receiver with guidance differed markedly. One caregiver described how she would lay her husband's clothes out for him as a way of clueing him as to the need to get dressed or to change clothes. Her interventions were designed to be subtle in order to protect him from the embarrassment of needing to be told when to dress and what to wear.

In contrast, a different caregiver was more directive in her efforts to help her husband keep track of his wallet. She described "training sessions" where she would tell him where to put the wallet and would then quiz him about its location. Instead of resolving the problem of the lost wallet, these episodes increased his agitation.

In addition, the decision about what type of strategy to use at different times played an important role in how effective the intervention was. Some caregivers seemed to have a keen sense for when it was appropriate to intervene directly to change the situation versus when it was more important to intervene indirectly or to go along with the situation. For example, one caregiver reported that there were times when she would reason with her husband, and other times when she would simply change the subject. Her choice of intervention depended on "the tone of his voice or the expression on his face". When her husband was agitated she would use less direct interventions in order to avoid increasing his agitation. Similarly, another caregiver described how she watches her husband for subtle cues that will tell her whether she needs to alter her intervention strategy when helping him locate a lost extension cord:

> I'll clue him and try to help him to think for himself where, through association, where that article might be. I don't push him with it. If I see that that's not working, then I'll say, "Well, I think perhaps if you would look in the shed." Or if you would look in a specific cupboard or something, then that might help him...If I see that he's just not making it, then I'll step in and say, "Well, let's see if we can find it". And then we go together and find it.

The caregiver's choice of intervention strategy and the manner in which she implemented the strategy were influenced by several factors. For example, the context in which the potentially problematic situation occured influenced the caregiver's intervention. One caregiver who was often confrontational with her mother at home would go along with her more when in public places.

The caregiver's appraisal of causality also seemed to influence her intervention in the situation. Caregivers who perceived that the care receiver's behavior was a result of situational circumstances were likely to avoid those situations (environmental management) or monitor the care receiver closely during those encounters that, in the past, posed problems. Caregivers who perceived that the behavior was a result of the care receiver's dementia and, subsequently, that the care receiver had little or no control over the behavior, were less likely to be confrontational in their intervention. Instead, they tended to intervene indirectly or less overtly. Caregivers who perceived the situation as a threat to their well-being often intervened in direct, antagonistic ways, while caregivers who were primarily concerned with the care receiver's well-being intervened with more tact and less confrontation.

## Filter Variables

Interviews with caregivers in this study suggest that the caregiver's management of potentially problematic situations was also influenced by the filter variables specified in the model. The relationships among these variables will be discussed in the next sections.

### Perceived Mutuality

Perceived mutuality is defined as the caregiver's assessment of the quality of her relationship with the care receiver. Important aspects of perceived mutuality include the caregiver's assessment of her past and present relationship with the care receiver, and her perception of whether caregiving has affected the quality of their relationship.

The influence of mutuality on the caregiver's management of potentially problematic situations was complex. In general, caregivers who reported having always had a good relationship with the care receiver were more likely to maintain a good relationship with the care receiver during caregiving than caregivers who had a poor, premorbid relationship with the care receiver. One caregiver reported that, since the onset of dementia, her husband has not wanted to be very far from her. However, she interprets this shadowing to mean that he likes to be with her. Because they have always gotten along well and have enjoyed each other's company, she does not interpret this to be a burden.

It seems that the basis for the good premorbid relationship was an important variable in the caregiver's perception of mutuality during caregiving. If the caregiving situation interfered with the basic foundation of the relationship, mutuality deteriorated during caregiving. For example, one caregiver reported that she had a wonderful relationship with her mother before the onset of caregiving.

> Our relationship was one of companionship and friendship and understanding and having similar interests in things. I mean we got along really great.

However, she stated that the relationship was good because "things always went mother's way". The caregiver reported that the mother's decreased ability to always get her way (as a result of the daughter's new role as caregiver) has had profound negative effects on the quality of their relationship.

> You can't relate as you used to. You know, the basis for the relationship is a good conversation, the sharing. That seems missing most of the time...it's just difficult to generate very much love, you know, under the circumstances because it already seems like it's never enough.

Mutuality seemed to be an important variable when it came to managing potentially problematic situations. In general, caregivers who reported high mutuality managed potentially problematic situations more effectively than caregivers who reported low, premorbid mutuality. The better the quality of the relationship, the less likely the caregiver was to assume that the behavior was under the care receiver's control. In addition, the better the mutuality, the more likely the caregiver was to perceive that the care receiver's well-being was at stake in the situation.

The caregiver's appraisal of the cause of the potentially problematic situation, the care receiver's control over his/her behavior, and her perception of what was at stake in the situation influenced the caregiver's choice of intervention strategy, its manner of implementation, and how effective the intervention was. One caregiver described her feelings toward her mother and their effect on caregiving:

> My opinion in taking care of somebody like this, you really have to love them, because if you didn't, myself, if I didn't love my mother I couldn't take care of her. I couldn't take care of her, I know I couldn't. I don't feel I could...But, beings she was the mother that she was, because she was a terrific mother...and knowing that that's not my mother. That isn't normal for her and she can't help what she's doing, she can't help it...I've learned this, you can't change the way they think. Once they get it in their mind, you can't change it.

## Guidelines for Care

The caregiver's guidelines for care are defined as the set of rules that guide her understanding of and intervention in potentially problematic situations involving the care receiver. In some situations, the set of rules were based on the caregiver's perception of how one generally deals with people with dementia. For example, one caregiver described how her mother's concern for her money was typical of someone with dementia:

> Money is a very crucial thing with them. They don't trust too many people and they are especially careful of their purses.

In other situations, the rules seemed to be tailored to the care receiver's specific needs. For example, one caregiver described the following:

> It's social activities that is better for him. If we go, we go down to the dance and we keep active, that seems to be better for him. And getting with people that he knows. So we usually go (to the Senior Center) on Thursday and then we have been going Friday afternoon.

In this study, there were marked differences between caregivers in the way in which they described the rules or principles that guided their management of potentially problematic situations. Some caregivers provided rich, detailed descriptions of what works under certain circumstances and what is called for in other situations. In contrast, some caregivers simply reiterated the guidelines they read in the literature or restated what others had told them they should and should not do. The caregivers in the first group seemed to manage potentially problematic situations more effectively than caregivers in the latter. It is as if the rules provided a useful starting place, but in order to increase her skill, the caregiver needed to learn how the rules could best be applied to her particular caregiving situation.

### Reflection on Care

Reflection on care is defined as the caregiver's attempts to learn how to manage potentially problematic situations by stepping back to think about how her interventions have influenced the situation, both positively and negatively. Caregivers who reflected on the care they provided intervened more effectively than caregivers who did not reflect on their situation. For example, the caregivers in this sample who seemed to manage potentially problematic situations most effectively frequently made statements such as "I found that by watching how he reacts..." or "What I have discovered is that...". They seemed to give careful thought to what they did and how the care receiver responded to their intervention. In contrast, caregivers who managed potentially problematic situations less effectively often described using the same intervention repeatedly with the same poor results. However, they demonstrated little insight into this pattern.

The more the caregiver reflected on her own care, the keener was her understanding of how the care receiver reacted to different situations and interventions and the more effectively she managed the situations. In addition, caregivers who reflected on what they did and how it worked seemed to develop guidelines for care that took into account the care receiver's idiosyncracies and special needs.

### Empathy

Empathy is defined as the caregiver's emotional and psychological identification with the care receiver. It refers to the extent to which a caregiver is able to put herself in the care receiver's position in order to better understand how s/he thinks and feels. The caregivers in this sample demonstrated a wide range of empathy for the care receiver's position. For example, when asked what they thought it might be like for the care receiver several caregivers were unable to say. One said she had not really thought about it, another stated she just did not know:

> It's hard for a normal mind to comprehend them being, I can't comprehend it being like that.

In contrast, several caregivers had thought about what it might be like to have dementia, or to be in need of care. One caregiver described:

> And I guess perhaps I look at myself again with the problems that I have and have had uh, due to my own illness and what I appreciate and what I don't appreciate within my own body or my own feelings towards my illness or my inabilities, the things that I have lost...in many ways the role of caregiver has almost switched back and forth, I've been the caregiver, he has been the caregiver, I've been the caregiver, he has been the caregiver and uh, I think you reach, you have more empathy when you've been in that position. Either as receiver or giver, you have far more empathy toward the situation.

Caregivers who had more empathy for the care receiver seemed to manage potentially problematic situations more effectively than caregivers who had less empathy.

In general, the higher the mutuality, the more empathetic the caregiver. It was almost as if the close relationship enabled the caregiver to think about what the care receiver might be going through, the losses, fear, and confusion. Similarly, caregivers who were more reflective about caregiving seemed to have more empathy.

### Knowing the Care Receiver

Knowing the care receiver refers to the caregiver's knowledge and understanding of the care receiver's premorbid personality, his/her dementia-related disabilities, and how s/he reacts or behaves in different situations. Increased knowledge about the care receiver enhanced the effectiveness with which caregivers managed potentially problematic situations.

The caregiver's knowledge of the care receiver's premorbid personality had an interesting influence on her appraisal of the care receiver's behavior. In situations where the care receiver's behavior was consistent with the caregiver's perception of his/her premorbid personality, she was less likely to attribute the cause of the behavior to dementia. For example, one caregiver described how her husband had gotten violent and verbally abusive during early stages of the disease. When asked if she was surprised by that she stated:

> Well that's a question! No, I guess I wasn't really surprised at all. I thought maybe he was getting a little worse, but he had acted like that before.

In contrast, when the caregiver perceived there was a discrepancy between the care receiver's behavior and his/her premorbid personality, she was more likely to attribute the cause of the behavior to the dementia.

> This is a man who has been extremely fastidious all his life. He worked in a bank which meant that he was up and in a white shirt and showered and was ready to go to work every morning. Suddenly I began to notice that when I would do the laundry there wasn't, you know, his clothing, that there hadn't been changes of clothing. There was no undergarments, there was no socks.

The caregiver's knowledge of who the care receiver was before the onset of dementia also influenced her appraisal of the care receiver's control over the situation and whose well-being was at stake. In the example cited above, the caregiver's perception that her husband's behavior was so different from what had been normal for him helped her to see that it was not something he was doing deliberately and allowed her to be concerned with his well-being. She stated:

> I realized that, back to teaching a child, I realized that it was going to become my responsibility to say, "It's time to shower, it's time to..." or else to lay the things out for him so that would give him recall that he should do something about that because it was not important to him. It became very unimportant to him. He's lost, seems to have lost the ability of knowing what goes with what...So, again, rather than to embarrass him or to put something upon him that seems difficult, I just take his clothes and lay them on the bed and don't say anything.

In addition to recognizing the disparity between the care receiver's behavior and his/her premorbid personality, some caregivers had an acute awareness of the nature of the care receiver's cognitive deficits and demonstrated a keen ability to detect subtle changes in the care receiver that indicated impending trouble. For example, one caregiver reported that when her husband was starting to get agitated,

> his face turns real red and then his eyes, he has, I don't know, his eyes get smaller, like he's deep in thought and then he gets, his hands start moving more; you can tell when he starts to get agitated and confused.

She used this insight to help her to intervene early to prevent escalation of the agitation. Other caregivers had an insightful understanding of how the care receiver would react to certain situations. For example, one caregiver declined to have her mother's Social Security checks put in the caregiver's name because she knew that would have a detrimental affect on her mother.

> They wanted to put the checks in my name and that would be devastating to her, if that check came in my name, it would kill her

Her mother watched the mail closely for the checks and looked forward to depositing them in the bank. The daughter understood that disrupting this routine would have adverse consequences for the mother.

Other caregivers did not seem to have insight into the situations that affected the care receiver adversely or what to look for in order to intervene early. For example, when asked whether there were certain situations that she knew were going to be more difficult than others, one caregiver stated, "No, it just seems to be real up and down". This caregiver was also unable to describe any of the subtle changes that may signal that her husband is getting agitated. Although this may reflect, in part, the unpredictable nature of dementia, it may also represent this caregiver's limited insight into her particular situation.

### Summary of Filter Variables

Analysis of these data suggest that in order to understand how caregivers managed potentially problematic situations involving the care receiver, one must also understand certain aspects of the caregiving situation in general. This study focused on the caregiver variables that seemed to influence management of potentially problematic situations. Conceptually, this model posits that several filter variables influenced the way in which the caregiver perceived, interpreted, and intervened in potentially problematic situations involving the care receiver.

These variables influenced the caregiver's appraisal of cause, control and stakes and influenced her choice and implementation of intervention strategy. More specifically, caregivers who reported more mutuality, empathy, reflection on care, and increased knowledge about the care receiver seemed to attribute the behavior either to the dementia or situational circumstances not under the care receiver's control, and did not perceive the situation as a threat to their own well-being. In contrast, caregivers who reported low mutuality, had little empathy for the care receiver, did not reflect on their care, and lacked insightful knowledge about the care receiver were more likely to see the care receiver's behavior as deliberate or volitional and perceive it as a threat to their well-being.

It is important to note that the effectiveness of the caregiver's management of potentially problematic situations influenced these filter variables as well. For example, caregivers who managed potentially problematic situations effectively were likely to perceive that there was less stress in their relationships with the care receiver. This may have helped to maintain or enhance mutuality. One caregiver described a relatively long siege of managing her husband's violent and aggressive behavior. She reported that when she finally realized that he was not behaving that way deliberately she was able to manage his violent behavior more effectively by not arguing with him and their relationship has improved greatly since then.

## Case Illustrations

In order to illustrate more clearly how this model can be used to understand the variables that influence how effectively caregivers manage potentially problematic situations involving the care receiver with dementia, two exemplars from the data will be presented. These situations were chosen because they demonstrate how the variables described in the model act in concert to influence the caregiver's management of potentially problematic situations.

### Potentially Problematic Situation Number One

One caregiver reported that the worst situations she has to manage are the repeated accusations by the care receiver that she is stealing his wallet. She reported that he hides the wallet in a place he feels is safe and then forgets where he put it. When he cannot locate the wallet, he accuses her of stealing it.

Appraisal of causality. This caregiver perceived that the behavior was caused by the care receiver's paranoia, resulting from his dementia. In addition, she stated that his concern over money is related to a gambling loss sustained in high school and more recent financial losses. She also stated that she thinks his paranoia about stealing is an expression of his subconscious awareness that his brain cells are being stolen by the dementia.

Appraisal of control. The caregiver vacillated on her perception of how much the care receiver is able to control this paranoid behavior. Although she stated that she understands that this is something a person with Alzheimer's will do, she also implied some volition on the part of the care receiver.

Appraisal of stakes. In this situation, the caregiver felt personally threatened by the care receiver's accusations. It was almost as if her honor was on the line.

Intervention. The caregiver used two different forms of convincing to manage the care receiver's behavior. She explained how she tries to explain to him about his paranoia, to convince him that he only thinks his wallet was stolen, that it is actually just misplaced. These explanations range from simple yet confrontational statements (e.g., "you're just paranoid") to more lengthy, thoughtful, explanations about the disease and how it results in paranoia. In addition she described how she works with him on consistently putting the wallet in the same place. She puts the wallet in the dresser and then quizzes him on the wallet's location.

<u>Effectiveness of management</u>. For the most part, neither of these strategies seemed to manage the care receiver's behavior effectively. He tends to get angry and more accusatory when she tries to explain about the paranoia, accusing her of trying to prove he is crazy so she can get all of his money. She described how when she finally yelled at him and scared him he backed down. One gets the sense that her efforts are an attempt to make herself feel better rather than because she is concerned about fears he may be experiencing. In addition, her desire to train him to put the wallet in the dresser is an unrealistic goal, given the degree of impairment he seems to have.

<u>Role of filter variables</u>. This couple has a history of low mutuality since their marriage four years ago. Finances have been a contentious issue prior to marrying when they signed prenuptial agreements protecting their respective assets. This behavior occurs at a time when the caregiver perceives that she is getting little if anything out of her

marriage or the caregiving situation. This seems to magnify her perception that the behavior is threatening to her well-being.

The caregiver has difficulty seeing the paranoia as part of the dementia. She lacks empathic understanding of the underlying emotions or needs that the paranoia may represent. Instead, she sees the accusations as consistent with his premorbid character. She questions whether she has two things going on, an abusive husband and a husband with dementia.

This caregiver also assumes that if she explains to her husband about dementia clearly enough or practices with him hard enough he will not accuse her of stealing. When these attempts fail she becomes frustrated, yet does not alter her strategy in any way. This failure to reflect on the effect of her actions seems to prevent her from intervening in a more skillful manner.

Finally, this caregiver demonstrates limited insight into the kinds of situations that increase her husband's accusatory behavior and the interventions that might effectively resolve his agitation. She does describe how, as soon as he walks out of his bedroom, she can tell whether or not he will start accusing her. However, she does not use that information to change her interaction with him. Instead, she braces for the worst and becomes quite defensive.

### Potentially Problematic Situation Number Two

Another caregiver reported that, on several occasions, her husband walked into the ladies rest room by mistake. He has done this at the Senior Center and at the beach.

Appraisal of causality. The caregiver perceived that this behavior was a result of her husband's dementia. She described that he gets confused at times and wanders into the wrong rest room.

Appraisal of control. The caregiver perceived that the care receiver had no control over the behavior. Instead, she tried to minimize the significance of the situation by stating that "he didn't know what he was doing".

Appraisal of stakes. In this situation the caregiver was primarily concerned for her husband's feelings. Witnesses to this incident reportedly made fun of him, angering the caregiver. She stated that she felt badly that he had been so embarrassed by the insensitivity of others.

Intervention. In order to guard against the recurrence of these episodes, this caregiver reported using several different types of interventions--environmental management, monitoring, and guiding. She avoids going to the Senior Center when she knows that people who make fun of her husband will be there. In addition, when they go out, she watches him closely and accompanies him to the rest room in order to point him in the right direction.

Effectiveness of management. She has been very successful in preventing the recurrence of this behavior. In addition, her practice of accompanying the care receiver seems to be a subtle way of keeping him out of trouble without drawing undue attention to his confusion, thus preserving his dignity in this situation. She down plays the seriousness of the incidents in order to protect him from embarrassment. The interventions used by this caregiver also seem to relieve her of the worry that the incident will be repeated. The additional burden of monitoring him and directing him seems to be offset by her assurance that he will not get into an embarrassing situation.

Role of filter variables. The caregiver in this situation reports high mutuality with her husband. She stated that she enjoys spending time with the care receiver and that they get along very well. Her concern for him in this situation appears to be a natural part of her love and affection for him.

This caregiver also seems to have a lot of empathy for the care receiver and his situation. She spoke of what it must be like for him to forget and how he must feel and seemed to be quite in tune with what he might be experiencing in any given situation. This empathy for him seemed to influence her ability to perceive his behavior as out of his control.

This caregiver also demonstrated keen insight into the situations that seemed to affect her husband adversely and is aware of the subtle cues that signal increasing agitation. Her close monitoring of him for signs of increasing problems seems to enable her to intervene early and in a preventative way to thwart problems.

### Analysis

These situations represent markedly different styles of managing potentially problematic situations involving the care receiver with dementia. One caregiver seemed to be much more effective in both managing the situation and in preserving both the care receiver's and her own sense of well-being. The other was much less effective and often escalated the problems in the situation, increasing her own and the care receivers agitation or anger. Differences between these caregivers were seen in the appraisals they made of the situations, the interventions they used to manage the behaviors, and the filters through which they perceived the situations. The model presented in this study suggests that these differences are central to the effectiveness of the caregiver's management of potentially problematic situations. In the next chapter, the theoretical and clinical implications of this model will be explored.

# Chapter 5: Discussion

In this chapter, I will discuss the results of the study, some of the theoretical, clinical, and ethical implications of the model, and identify areas for further research.

## Discussion of Results

An analysis of the hypothesized relationships between concepts in the model was reported in the previous chapter and so will not be repeated here. However, it is important to address some conceptual issues related to the study methods. First, it is important to note that this sample was not drawn randomly and may not be representative of all caregivers to persons with dementia. Most obviously, there were no male caregivers in the sample. Several male caregivers were approached to participate in the study. Two refused because they denied that their wives had any problems with their memory (despite chart data to the contrary), and one refused because he was overwhelmed by his situation. Consequently, it is not possible to draw conclusion about how these results may apply to male caregivers.

The participants in this study were, however, purposefully selected to represent a wide range of caregiving situations. Some caregivers experienced relatively low amounts of stress and managed potentially problematic situations with confidence. Others were in extremely stressful situations where they questioned how long they could continue caregiving and managed problem situations with difficulty. In addition, some subjects had been caregiving for quite a long time (7 to 10 years), while others were relative newcomers (less than a year). Still, despite this range of caregiving situations, it will be necessary to test this model on a randomly drawn sample of caregivers in order to determine how well it describes the management of potentially problematic situations and explains the effectiveness with which caregivers manage these problems.

## Theoretical Implications

It is important to view the findings from this research with respect to related theoretical frameworks. In this section, I will discuss some of the differences and similarities between this model and the model of stress and coping proposed by Lazarus and Folkman (1984) and examine how these findings fit with the extant literature on family caregiving.

### Stress and Coping

In an attempt to explain why similar stressors are associated with different levels of negative outcomes, Lazarus and Folkman (1984) postulate that certain cognitive and behavioral processes (i.e., cognitive appraisal and coping) act to mediate stressful person-environment relationships. They define cognitive appraisal as a process "through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being, and if so, in what ways" (Folkman, Lazarus, Dunkel-Schetter, Delongis, and Gruen, 1986, p. 992). Coping is defined as "the person's constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources" (p. 993). Lazarus and Folkman (1984) think that appraisals are influenced by commitments and beliefs that overshadow the person's interpretation of all stressful situations.

The findings from this study are congruent with Lazarus and Folkman's theory in several ways. For example, I found that the caregiver's perception and interpretation of the potentially problematic situation (the person-environment relationship) influenced the caregiver's strategy for managing or coping with it. Similarly, I found that certain caregiver characteristics (guidelines for care, empathy) influenced her appraisal of the situation in important ways. However, there are important differences between these two models that must be pointed out.

First of all, Lazarus and Folkman identify two dimensions of cognitive appraisal that they think are important to any encounter--primary and secondary appraisal. Primary appraisal is the assessment of whether the encounter is stressful and if so, in what way (threat, harm or loss).

Secondary appraisal is the caregiver's assessment of what kind of coping the situation calls for and whether s/he has the resources to implement that strategy. In contrast, the dimensions of caregiver appraisal that I identified in this study were causality, control, and stakes.

One major difference between these two conceptions of appraisal is the latter's inclusion of concern about another individual. In situations where an individual need only be concerned about him or herself, Lazarus and Folkman's definition of appraisal seems appropriate. However, in caregiving situations, the caregiver must also be concerned about the welfare of the care receiver. Consequently, it seems important to include her appraisal of what is at stake for the care receiver in potentially stressful encounters.

Other important differences between the two conceptions of appraisal are the issues of cause and control. Lazarus and Folkman do not address the issue of causality in their definition of primary appraisal. However, it is difficult to say at this time whether the appraisal of causality is unique to situations involving a dependent person with dementia, or whether elements of causality are germane to appraisals of all stressful encounters. Additional research focusing on that question is needed to resolve the issue.

Lazarus and Folkman do address the issue of control. However, they are primarily interested in a person's appraisal of whether s/he is able to handle the stressful person-environment relationship. In contrast, the effectiveness with which caregivers managaged potentially problematic situations involving the care receiver seemed more dependent on the caregiver's perception of the care receiver's control rather than her own. Although caregivers were asked about their confidence in their ability to handle the situations, self-efficacy did not seem to be a big factor in managing these situations.

A final area where the two models diverge somewhat involves the coping or intervention strategies. The caregiver interventions identified in this study were not deemed to be inherently good or bad. Instead, their effectiveness is thought to depend on the manner in which they are implemented and how appropriate they are for the situation. Likewise, Lazarus and Folkman maintain that coping strategies are not, in and of themselves, good or bad. Instead, they are either successful or unsuccessful in alleviating the threat, harm or loss of the situation. However, it is not clear from their writing whether Lazarus and Folkman think that the way in which the coping strategy is employed will influence its success or whether the person's ability to recognize what situation calls for what coping strategy influences the outcomes in anyway. In addition, these two models differ in that Lazarus and Folkman describe a generic set of coping strategies that could apply to almost any stressful encounter. In contrast, I described a set of interventions that are specific to the management of potentially problematic situations involving someone with dementia.

## Caregiver Literature

It was noted in Chapter 2 that several intra and interpersonal mediators, which influence the outcomes of caring for someone with dementia, have been identified in the literature. Among these were social support, quality of the caregiver-care receiver relationship, appraisal, and coping strategies. The results from this study support these earlier findings, suggesting that the caregiver's appraisal of the potentially problematic situation and the strategy she uses influence how effectively she manages the situation. In addition, the caregiver's perception of the quality of her past and present relationship are thought to influence her management of problem situations dramatically.

However, this study provides greater depth regarding what some of the salient aspects of these intrapersonal mediators are and hypothesizes about the mechanisms through which they influence caregiving more specifically. For example, the findings in this study suggest it is not enough to know the quality of the caregiver's current relationship with the care receiver. Instead, an understanding of the past relationship and how caregiving has affected mutuality is also considered essential.

One of the most significant contributions made by this study is the analysis of caregiver interventions. In general, the caregiver literature on interventions has focused on interventions used by health professionals to assist the caregiver. These interventions generally involve education, support, and/or respite. However, very little is written about what specific strategies caregivers might use to manage potentially problematic situations and how they might implement them to maximize effectiveness. The results from this study outline specific strategies used by caregivers and examines the elements that seem to enhance their effective implementation. Although further testing of this model is needed, exploring the efficacy of specific interventions to be used by caregivers may represent an important next step in this area.

### Alternative Conceptualizations

Despite the model presented in the previous chapter, it is recognized that these data could have been conceptualized in different ways. For example, early in the analysis I noted that the caregiver's transition to caregiving seemed to be an important variable in how effectively she managed. The more the caregiver was exposed to episodes of care receiver dysfunction, the more she was able to understand that s/he might not be acting deliberately. However, because this was not a longitudinal study, it was not possible to explore the facets of the transition to caregiving. Consequently, it is difficult to hypothesize how the duration of caregiving may influence management of potentially problematic situations. Until further research in that area can be conducted, it will be important to recognize the limitations of a static view of the caregiving process.

Another conceptualization of these data that was considered during analysis concerns the caregiver's seemingly different levels of skill in managing the problem situation. Several caregivers seemed to be very skillful in managing different situations, either preventing problems, or controlling escalation in ways that preserved both her own and the care receiver's well-being. In contrast, other caregivers were limited in their abilities to manage potentially problematic situations, intervening in ways that, in one case, bordered on abuse. Consequently, it was thought that a model of novice to expert caregivers, similar to Benner's work (1984), might explain the differences between caregivers. However, this approach had limited clinical utility because it emphasized characteristics of the individual that may be difficult to transfer to others, rather than aspects of the intervention that might more easily be taught.

Of the different possible conceptions of the data, the model presented in Chapter 4 was selected for two reasons. First, it seemed to explain the differences in effectiveness with which family caregivers managed potentially problematic situations. This explanation also seemed to apply to a variety of problem situations. Second, the model seemed to have important clinical utility. The concepts in the model seem to be ones that offer insight on how one might intervene with family caregivers to manage problem situations more effectively. The clinical implications of the model will be discussed further in the next section.

## Clinical Implications

The results from this study have important implications for clinical practice with family caregivers to persons with dementia. Specifically, this model suggests that the effectiveness with which caregivers manage potentially problematic situations involving the care receiver depends, in part, on her perception and interpretation of the situation, and the intervention strategies she uses. It also postulates that certain perceptions and intervention strategies are more likely to result in effective management under certain conditions than others. By assessing these variables it might be possible for health professionals to determine specific areas where formal interventions could enhance effectiveness.

For example, in situations where the caregiver perceives that the care receiver is behaving deliberately, it might be possible to intervene to demonstrate that the behavior is a result of the dementia. This may allow the caregiver to intervene more effectively than when she sees the behavior as intentional. Similarly, by teaching caregivers to reflect on the situational circumstances that escalate problems and/or the intervention strategies that do or do not work, they may learn to manage problem situations more effectively.

Another area where the model might influence clinical practice is in the assessment of simultaneous stressors. It was noted that caregivers who were already in stressful situations with few resources had difficulty managing problem situations. Assessment of the simultaneous stressors may help to identify caregivers who need some respite before attempting to alter the way in which they manage problem situations.

In situations where there has been a long-standing history of conflict between the caregiver and care receiver, it may not be possible to change the pattern of interaction in order to influence the caregiver's perceptions of the care receiver's behavior. Assessing the caregiver's perceived mutuality may help to identify caregivers who may need to be counseled out of providing direct care.

Finally, this model may be useful in restructuring the content of caregiver education programs. Currently, these programs tend to provide the caregiver with information about dementia and various support and respite services. I believe it is necessary to build on that information with more specific ideas of how to reinterpret problem situations and manage them more effectively.

## Ethical Considerations

As with any research endeavor, it is important to consider some of the ethical issues raised by the findings of this study. This study has focused almost entirely on the caregiver. By proposing that the caregiver's perceptions, interpretations and interventions influence how effectively she manages potentially problematic situations involving the care receiver it might be inferred that she is to blame when the problems are not managed effectively. A fine but distinct line must be drawn between acknowledging that a caregiver may be able to act to resolve some of the difficult situations she encounters in caregiving, and suggesting that she is responsible for the problems that are not managed successfully. Use of this model to blame a caregiver for the difficult situations she experiences would be considered an inappropriate interpretation of the concepts.

Another ethical issue concerns the possibility of losing sight of the larger caregiving picture by focusing on isolated situations. The author recognizes that a caregiver may effectively manage all of the potentially problematic situations encountered in caregiving and still find her situation extremely stressful. The complex nature of the caregiving must be seen as more than the sum of problem episodes. I have chosen to focus on one aspect of caregiving and it is important to recognize there are other, potentially stressful aspects that are not addressed in this model.

Finally, in a related concern, it is important to recognize that interventions designed to enhance the effectiveness with which the caregiver manages problem situations may, in the long run, be detrimental. By making parts of caregiving more manageable, one risks curing the symptoms that are signals to a more serious problem. In other words, interventions that increase the caregiver's ability to manage potentially problematic situations may make it more difficult for her to extricate herself from an otherwise intolerable situation. Consequently, a better understanding of those factors that indicate the need for alternative care arrangements is needed.

## Further Research Recommendations

It is important to recognize that a great deal of research has been conducted in the area of family caregiving for persons with dementia. This study was influenced strongly by the work done by others in the field. Still, there remain unanswered questions and areas that merit further inquiry. In this section, I will explore some of the topics in need of further research.

It was stated earlier that this research is the first step in a program of research designed to develop nursing interventions to assist caregivers in managing potentially problematic situations involving the care receiver with dementia more effectively. The next step in this program of research is a methodological study to develop and test instruments to measure the central variables in the model. Following that, a descriptive, quantitative study is needed to test the hypothesized relationships among the variables in the model. Finally, research developing and testing interventions derived from the model is needed in order address some of the clinical issues faced by family caregivers.

In addition to the above program of research, other research is needed in this area. As mentioned earlier, it seems important to gain a better understanding of the transition caregivers go through in learning, accepting and integrating the meaning of the care receiver's dementia in their daily care. A longitudinal study that examines how caregivers' perceptions and interpretations of their situation change over time could offer important insight into the variables that influence their ability to manage problem situations.

In this study, it was recognized that certain care receiver, dyadic, and situational variables seemed to influence the caregiver's effectiveness in managing problem situations. However, it was not within the scope of this study to explore their effect more specifically. A study that explores these variables is necessary in order to gain a more comprehensive understanding of the differences across situations and across caregivers.

## Summary

The purpose of this study was to identify and define the variables central to a caregiver's management of potentially problematic situations involving the care receiver with dementia. A model that posits the relationships between these variables was presented. This model suggests that the caregiver's effectiveness in managing potentially problematic situations involving the care receiver is mediated by two sets of variables, situational variables and filter variables.

Included in the situational variables are the potentially problematic situation, the caregiver's appraisal of the situation and the interventions she uses to manage the situation. The filter variables are those less transient variables that characterize the caregiver's general approach to caregiving. They include the caregiver's perceived mutuality, empathy, reflection on care, knowledge about the care receiver, and guidelines for care.

Conceptual definitions for each of the variables in the model were presented and the hypothesized relationship among them discussed. In addition, two exemplars from the data were presented in order to illustrate how the model can be applied to different situations, and how the variables help to explain differences in how the situations were managed.

The model is viewed as a tentative explanation of the differences in caregiver effectiveness in managing potentially problematic situations. Further research is needed in order to develop and test nursing interventions derived from the model.

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# Appendix A

# Interview Guide

1. What is your relationship to (CARE RECEIVER)? You are his/her:

| | |
|---|---|
| Spouse | 1 |
| Child | 2 |
| Child-in-Law | 3 |
| Other relative | 4 |
| Other non-relative | 5 |

2. Do you live with (CARE RECEIVER)?

| | |
|---|---|
| No | 0 |
| Yes | 1 |

3. How long has (CARE RECEIVER) had problems with his/her memory? ______________________________

4. How long have you been caring for (CARE RECEIVER)?

______________________________

5. Often times when someone develops dementia or memory problems, they begin to act differently. Has this happened with (CARE RECEIVER)?. Could you tell me a little about that?

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

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______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

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______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

6. Sometimes when someone has dementia they say and do things that are troublesome for the caregiver. Has that ever happened to you? Could you tell me a little about how you have had to manage those situations?

7. Could you tell me about a specific instance when that happened? What did (CARE RECEIVER) do and say?

8. Could you tell me about another time when that happened? What did (CARE RECEIVER) do and say?

9. Could you tell me about another time when that happened? What did (CARE RECEIVER) do and say?

10. I am interested in both the behaviors that are difficult for the caregiver to manage and those that are easier for her to cope with. Could you tell me about some situations in which (CARE RECEIVER's) behavior was easier/harder for you to deal with? For example, what are the kinds of things that happen that you tell your best friend about? The things that happen in a typical day?

11. Are there other ways in which (CARE RECEIVER) has acted differently that you would like to share with me?

## PROBES

12. Why do you think s/he did that? What do you think caused that behavior? What do you think was going on in his/her head?

13. What were you thinking and feeling at the time? What was your reaction? Was that a problem for you? Why or why not?

14. What else was going on at the time? What kind of day had you been having? What time did it happen? Where were you when it happened?

15. Did you think that anything could be done to change the situation? Did you think there was anything you could do to change it? Did you feel that you were prepared to handle the situation?

16. What did you do when (CARE RECEIVER) did that? How did you respond? What did you say? What did you hope that would do?

17. What happened when you did that? How did (CARE RECEIVER) react when you did that?

18. How effective was that? What do you consider success? Would you say you were successful in resolving that problem?

19. Overall, how hard was it for you to manage this situation? How much strain (or stress) did this situation cause you?

20. Has (CARE RECEIVER) ever done this before? What happened then? How was that situation different from this one?

21. Has there been a change in how you have viewed what has caused (CARE RECEIVER's) behavior? How did that change happen?

Now I would like to ask you some questions about how much stress you are experiencing in your current situation.

22. How much stress do you feel from managing (CARE RECEIVER'S) behavior problems?

| | |
|---|---|
| No stress ..................... | 1 |
| Very little stress ............ | 2 |
| Some stress ................... | 3 |
| A lot of stress ............... | 4 |
| Overwhelming stress ........... | 5 |

23A. From my discussions with many caregivers, I know that for some people caregiving is very confining, while for others it is not. How much confinement do you feel because of all the caregiving things you have to do for (CARE RECEIVER)?

| | |
|---|---|
| None at all ................... | 0 |
| A little confinement .......... | 1 |
| Some confinement .............. | 2 |
| A lot of confinement .......... | 3 |
| Overwhelming confinement ...... | 4 |

(If respondent does not understand the word confince, say, "Do you feel restricted in being able to do the things you want to do because of all the caregiving things you have to do for (CARE RECEIVER)?)

23B. How often would you say that taking care of (CARE RECEIVER) is very difficult? Would you say: (READ CHOICES)

| | |
|---|---|
| Rarely ........................ | 1 |
| Sometimes ..................... | 2 |
| Much of the time .............. | 3 |
| Always ........................ | 4 |

23C. How much stress do you feel because of all your obligations, including taking care of (CARE RECEIVER)? Do you feel (READ CHOICES):

| | |
|---|---|
| No stress ..................... | 1 |
| Very little stress ............ | 2 |
| Some stress ................... | 3 |
| A lot of stress ............... | 4 |
| Overwhelming stress ........... | 5 |

23D. In the balance, would you say that the positive aspects of caring for (CARE RECEIVER) outweigh the negative, that the negative aspects outweigh the positive, or that the positive and negative aspects are about equal?

| | |
|---|---|
| Negative outweigh positive .... | 1 |
| Negative and positive are about equal ................ | 2 |
| Positive outweigh the negative.................... | 3 |

24. AFFECT BALANCE SCALE

During the past few weeks, did you ever feel:

| | NO | YES |
|---|---|---|
| 24A. Particularly excited or interested in something? .................. | 0 | 1 |
| 24B. So restless you couldn't sit long in a chair? .......................... | 0 | 1 |
| 24C. Proud because someone complimented you on something you had done? ........... | 0 | 1 |
| 24D. Very lonely or remote from other people? ................................. | 0 | 1 |
| 24E. Pleased about having accomplished something? .................. | 0 | 1 |
| 24F. Bored? .................................. | 0 | 1 |
| 24G. On top of the world? ...................... | 0 | 1 |
| 24H. Depressed or very unhappy? ................ | 0 | 1 |
| 24I. That things were going your way? .......... | 0 | 1 |
| 24J. Upset because someone criticized you? .......................... | 0 | 1 |

## PERSONAL CHARACTERISTICS

25. What is your birth date?

__ __ / __ __ / __ __ __ __
Month Day Year

26. Caregiver's gender

| | |
|---|---|
| Male | 1 |
| Female | 2 |

27. What is your race?

| | |
|---|---|
| White | 1 |
| Black | 2 |
| Asian | 3 |
| Hispanic | 4 |
| Native American | 5 |
| Mixed Race | 6 |
| Prefer not to answer | 7 |
| Blank | 9 |

28. What is the highest grade in school that you completed?

| | |
|---|---|
| Never attended school | 0 |
| Attended grade school | 1 |
| Completed 8th grade | 2 |
| Attended high school | 3 |
| Completed high school | 4 |
| Post-high school training | 5 |
| Attended college | 6 |
| Completed college | 7 |

29. Here is a list of annual income categories. Which annual income category comes closest to the total amount of your household income?

| | |
|---|---|
| Under $3,000 per year | 01 |
| $3,000 - $5,999 | 02 |
| $6,000 - $9,999 | 03 |
| $10,000 - $14,999 | 04 |
| $15,000 - $24,999 | 05 |
| $25,000 - $34,999 | 06 |
| $35,000 - $44,999 | 07 |
| $45,000 - $54,999 | 08 |
| $55,000 - $64,999 | 09 |
| $65,000 - $74,999 | 10 |
| $75,000 and over | 11 |
| Don't know | 88 |
| Blank/Refused | 99 |

30. Care receiver's gender

| | |
|---|---|
| Male | 1 |
| Female | 2 |

31. Care receiver's race

| | |
|---|---|
| White | 1 |
| Black | 2 |
| Asian | 3 |
| Hispanic | 4 |
| Native American | 5 |
| Mixed Race | 6 |
| Prefer not to answer | 7 |
| Blank | 9 |

32. What is the highest grade in school that (CARE RECEIVER) completed?

| | |
|---|---|
| Never attended school | 0 |
| Attended grade school | 1 |
| Completed 8th grade | 2 |
| Attended high school | 3 |
| Completed high school | 4 |
| Post-high school training | 5 |
| Attended college | 6 |
| Completed college | 7 |

33. Which annual income category comes closest to the total amount of (CARE RECEIVER'S) household income?

| | |
|---|---|
| Same as caregiver's | 00 |
| Under $3,000 per year | 01 |
| $3,000 - $5,999 | 02 |
| $6,000 - $9,999 | 03 |
| $10,000 - $14,999 | 04 |
| $15,000 - $24,999 | 05 |
| $25,000 - $34,999 | 06 |
| $35,000 - $44,999 | 07 |
| $45,000 - $54,999 | 08 |
| $55,000 - $64,999 | 09 |
| $65,000 - $74,999 | 10 |
| $75,000 and over | 11 |
| Don't know | 88 |
| Blank/Refused | 99 |

# Appendix B

Oregon Health Sciences University
Informed Consent

## TITLE

A Qualitative Study of Family Caregiver's Management of Potentially Problematic Behaviors of Persons with Dementia

## PRINCIPLE INVESTIGATOR

Terri Harvath, RN, MS
(Doctoral Student)

Phone: 503-279-7796

## PURPOSE

Terri Harvath, a doctoral student in the School of Nursing, is doing a research project designed to understand more about how family members care for someone with dementia. She wants to find out how caregivers manage potentially problematic behaviors of care receivers that are associated with dementia.

## PROCEDURES

I understand that, if I agree to participate in this project, Ms Harvath will ask me questions about how I manage behavior problems that are related to (CARE RECEIVER'S) dementia or memory problems. She will also ask me some questions about how much stress I have and how I am feeling. The interview will take about 1-2 hours. Ms Harvath may call me to arrange a second interview. I understand that the interviews will be tape recorded. Following transcription, the tapes will be destroyed.

## RISKS AND DISCOMFORTS

Some of the questions may touch on painful experiences that are upsetting to me. I understand that if, during the course of the interview, elder abuse is discovered Ms. Harvath is required to report this to Senior Services Division.

## BENEFITS

I understand that I may not benefit directly from participating in this study, but that it might help other people in the future.

## CONFIDENTIALITY

Neither my name nor my identity will be used for publication or publicity purposes.

## COSTS

There are no costs involved for me as a subject.

## LIABILITY

I understand that it is not the policy of the Department of Health and Human Services or any agency funding the research project in which I am participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the state is covered by the State Liability Fund. If I suffer any injury from the research project, compensation would be available only if I establish that the injury occurred through the fault of the University, its officers, or employees. If I have further questions, I can call Dr. Michael Baird at 279–8014.

Ms Harvath has agreed to answer any questions I may have. I may refuse to participate in this study or withdraw at any time without affecting my relationship with or treatment at the Oregon Health Sciences University. I understand that I will be given a copy of this consent form. My signature below indicates that I have read the foregoing and agree to participate in this study.

Caregiver's Name Date

Witness' Name Date

# Abstract

Caring for an older family member with dementia can be a very difficult and frustrating experience. Some of the difficulty occurs while managing potentially problematic situations involving the care receiver's behavior. A qualitative study using grounded theory (Glaser & Strauss, 1967) was conducted to identify and define the variables central to a caregiver's management of potentially problematic situations involving the care receiver with dementia. Using a semi-structured interview guide, family caregivers (n=10) were asked to describe problem situations they encountered during caregiving. The data were analyzed using constant comparative analysis to identify and define concepts thought to be central to the management of problem situations involving the care receiver.

A model that posits the relationships between these variables was presented. This model suggests that the caregiver's effectiveness in managing potentially problematic situations involving the care receiver is mediated by two sets of variables, situational variables and filter variables. This study serves as the basis for the next methodological study designed to develop and test instruments measuring the concepts central to caregiver management of potentially problematic situations.