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To the Graduate Council:

I am submitting herewith a dissertation written by Janet Witucki entitled "Help-seeking by older wife caregivers of demented husbands: a grounded theory approach." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Martha Raile Alligood, Major Professor

We have read this dissertation and recommend its acceptance:

Carol Seaver, Debra Wallace, Jean Skinner

Accepted for the Council:

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Vice Provost and Dean of the Graduate School


(Original signatures are on file with official student records.)


To the Graduate Council:


I am submitting herewith a dissertation written by Janet M. Witucki entitled "Help-seeking by Older Wife Caregivers of Demented Husbands: A Grounded Theory Approach." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.


Martha Raile Alligood, Major Professor


We have read this dissertation
and recommend its acceptance:


Carol Seavor


Debra Wallace


Jean Skinner

Accepted for the Council:


Associate Vice Chancellor and
Dean of the Graduate School

**HELP-SEEKING BY OLDER WIFE CAREGIVERS
OF DEMENTED HUSBANDS:
A GROUNDED THEORY APPROACH**

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Janet Marie Witucki
May 2000

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DEDICATION

Elmer A. Witucki

6/29/44- 1/27/99

This dissertation is dedicated to the memory of my beloved husband, Elmer A. Witucki. His love, encouragement, and support started me on this journey and sustained me during the inception of this work. His spirit and love have remained guiding forces seeing me through to its completion. "They that hope in the Lord will renew their strength, they will soar as with eagles' wings; They will run and not grow weary, walk and not grow faint" (Isaiah 41:31).

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Thanks is also extended to the individuals and agencies that assisted me with the recruitment of participants for this study. Special recognition is extended to the wife caregivers who gave up very valuable time to share their life experiences and stories with me. Those stories will remain with me for a long time. Acknowledgment also goes to the Gamma Chi Chapter of Sigma Theta Tau for a research grant that partially funded this dissertation study.

Finally, I wish to thank the many friends I have made during this journey. I especially am indebted to Alice, Barb, and Clara for being there for me through the good times and bad. They have truly been there when I needed them.

ABSTRACT

The purpose of this study was to gain an understanding of patterns of help-seeking by older wife caregivers of demented husbands. Essential to an understanding of service utilization is an understanding of the more basic process of help-seeking. Research to date has largely concentrated on help-seeking as a variable, rather than as an independent entity.

Grounded theory methodology with a nursing perspective of health as expanding consciousness, was used to explore interactions, thoughts and feelings associated with patterns of help-seeking by eleven older wife caregivers and allowed for a more holistic view of the process of help-seeking by these older women. This methodology led to discovery of a new substantive theory entitled "Help-seeking choices: Taking one day at a time" which was grounded in reality as experienced by the participants and illuminates help-seeking for this group of caregivers. The core category of reaching out/reaching within described the main phenomena of wives reaching out to involve both informal and formal sources and reaching within themselves to manage care and seek help on a day-to-day basis. Wives made choices to employ strategies of avoiding, shouldering and facing to accomplish continuing to provide care at home for the husbands. These choices were influenced by a myriad of facilitating and hindering intervening conditions.

Understanding obtained from the study indicates that earlier screening and intervention are essential to assisting with identification of dementia and to help caregivers realize that a problem exists. Further suggestion is for more comprehensive case management across health care settings for this group, and a recognition of the impact of previous experiences on future health choices by these caregivers. The importance of pattern recognition which enables caregivers to view, seek, and manage their husbands' health care in creative ways is also indicated. Understanding gained may lead ultimately to the development of interventions which can increase the effectiveness of help-seeking patterns, result in more appropriate utilization of formal and informal resources, reduce burden and stress associated with the caregiving role, and assist women to sustain the caregiving role.

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CHAPTER ONE

Introduction

Help-seeking by family caregivers of demented persons is poorly understood, but has important implications for the well-being of caregivers, demented persons, and society as a whole. Health care providers, researchers, and policy makers have attempted to understand the complexities of help-seeking by family caregivers of demented persons for years in an attempt to explain the reluctance of caregivers to utilize available community services. Despite much research into utilization of community services however, an understanding of patterns of help-seeking by these caregivers remains obscure.

Understanding help-seeking patterns by family caregivers has importance because home care for the approximately three to six million elderly in the United States with moderate to severe dementia (Office of Technology Assessment, 1990) is provided primarily by family caregivers, the majority of whom are women (Alzheimer's Association, 1995). These caregivers provide many hours of care weekly, and have been involved in the caregiving experience for an average of four years or more (Alzheimer's Association, 1996). As a result of this prolonged caregiving burden, caregivers experience a variety of negative physical, psychological, social, and financial effects (Almberg, Grafstrom, & Winblad, 1997; Alzheimer's Association, 1996; Baldwin, 1988; Brown, 1991; Cohen & Eisdorfer, 1988; Vitaliano, Dougherty, & Seigler, 1994).

Negative caregiving effects are encountered primarily by women because female caregivers are the primary source of help for elders with dementia living at home. While most frail elderly men are cared for at home by their wives, elderly frail women are more likely to be cared for by adult daughters or daughters-in-law (Robinson, 1997; Shanas, 1979; Stoller & Earl, 1983). Further, women caregivers in their late middle to elderly years carry a disproportionate caregiving burden as a consequence of the late onset of most dementing illnesses (Office of Technology Assessment, 1987).

Older women who are caregivers have been identified as an at-risk population and as "hidden patients" in the current health care system (Ostwald, 1997; Robinson, 1986, 1988). An article discussing the impact of caregiving on women stated "As we are busy caring for others, quite possibly no one is looking after us" (Covan, 1997, p. 336). Frequently older and middle aged women caregivers suffer from a myriad of age-related physical problems themselves. Exacerbation of high blood pressure, disturbances in gastrointestinal functioning, extreme weight gain or loss, and generalized fatigue have been reported as consequences of the burden of caregiving (Baldwin, 1988) as well as exhaustion, heart attack, and disintegration of knee joints and back discs (Crossman, London, & Barry, 1981). Worsening of physical conditions in these women caregivers reduces their ability to provide adequate care for the demented family member, putting both the women caregivers and the demented individuals at risk.

In addition to physical problems, older wives and daughters are also likely to experience more psychological distress, anxiety, and burnout than other family caregivers as a result of the burden of caring for a demented elderly person (Almberg et

al., 1997; Anthony-Bergstone, Zarit, & Gatz, 1988; Fitting, Rabins, Lucas, & Eastham, 1986). Women caregivers also experience more loss of self and more caregiver role engulfment than male caregivers (Skaff & Pearlin, 1992). Higher stable rates of depression (Schultz & Williamson, 1991) and helplessness (Batt-Leiba, Hill, Johnson, & Bloch, 1998) have also been reported. Further, increased usage of sleeping medications and psychotropic medications have been substantiated among female caregivers (Pruchno, Michaels, & Potashnik, 1990). High levels of distress, anxiety, burnout, depression, and use of medication then, provide evidence of negative psychological effects of the caregiving experience for these women.

It is apparent from the literature that women caregivers suffer a variety of adverse effects from the prolonged demands of the caregiving experience. However, while these women report the need for assistance, they often do not seek formal help or utilize formal care services until either a crisis point is reached, or as a last resort (Collins, King, & Kokinakis, 1994; Montgomery & Borgatta, 1989; Stone, Cafferata, & Sangl, 1987; Straw, O'Bryant, & Meddaugh, 1991). Decisions to ask for help from family members or use community services have been reported by familial caregivers of demented individuals to be challenging (Wackerbath, 1997). In fact, many caregivers delay seeking a memory related medical evaluation for their relative until several years after the onset of symptoms (Haley, Clair, & Saulsberry, 1992). Research substantiating underutilization of respite care, day care, paid caregivers, counseling services, and support groups is abundant, despite the fact that such services could lessen the detrimental effects of the caregiving experience, contribute to caregiver well-being, and

delay institutionalization of the demented elder (Caserta, Lund, Wright, & Redburn, 1987; Greene & Monahan, 1989; Lundervold & Lewin, 1987; Maslow, 1990; Mittleman et al., 1993; Mohide et al., 1990).

Much research has been conducted regarding caregiver service utilization and numerous factors have been identified as contributing to caregiver's underutilization of community services. Knowledge, time, accessibility, scheduling, cost, care receiver needs, caregiver characteristics, attitudes, values, beliefs, and family units have all been identified as affecting caregivers' decisions to seek and accept available community services (Bass & Noelker, 1987; Caserta et al., 1987; Collins, 1992; Collins, Stommel, King, & Given, 1991; Gonyea & Silverstein, 1991; Lawton, Brody, & Saperstein, 1989a, 1989b, 1991; Liken & King, 1995). However, when interventions were developed which addressed these issues, caregivers continued to underutilize available services (Gwyther, 1989; Lawton et al., 1989a, 1989b; Montgomery & Borgatta, 1989). Additionally, Wolinsky and Arnold (1988) after examining literature on prediction of use of health services among the elderly, reported that the amount of variance explained by complex multivariate models rarely exceeded 20%. Lack of both effectiveness of interventions and the ability to predict significant variance in service utilization indicates that service underutilization and more importantly, patterns of help-seeking by family caregivers of demented persons is poorly understood.

Little is known about patterns of help-seeking in the elderly and particularly in elderly caregivers. Much available elderly help-seeking research concentrates on studies concerning help-seeking for mental health problems. Additionally, other research on

this subject has explored help-seeking as a variable, rather than as an independent entity, thereby failing to contribute to an understanding of patterns of help-seeking.

In studies relating help-seeking and mental health, help-seeking has been correlated with a variety of mental health concepts such as depression, life satisfaction, coping, and social support, and has also been explored as a variable in relation to mental health problems and psychological distress (Knisely & Northouse, 1994; Phillips & Murrell, 1994; Rapp, Schumaker, Schmidt, Naughton, & Anderson, 1998; Ray Raciti, & MacLean, 1992). In one study of 78 wives who served as primary caregivers to husbands with irreversible memory impairment, attitude toward asking for help was significantly related to depression (Robinson, 1989). Self-help and help-seeking were significantly correlated with greater life satisfaction among 120 healthy elders in a study by Zauszniewski (1996), and with reduced caregiver stress in daughters in a study by McCarty (1996). However, help-seeking as a dimension of coping, was significantly associated with well-being in caregiver spouses but not daughters in a study by Quayhagen and Quayhagen (1988). Finally, significant correlations were found between social support and elderly help-seeking behavior in several studies (Auslander & Litwin, 1990; Knisely & Northouse, 1994; Phillips & Murrell, 1994). These significant linkages of help-seeking to mental health, caregiver well-being, life satisfaction, and social support demonstrate the importance of this concept for caregivers.

Several qualitative studies have explored selected aspects of help-seeking in attempts to obtain an understanding of this phenomena from the participant's perspective. King, Collins, and Liken (1995) identified a theme of "family boundaries

govern help-seeking” in a study examining community service utilization by 34 dementia caregivers. In this study, observed boundaries of the family system were described by caregivers as being a part of understanding how family problems were appropriately handled. A lack of acceptability of assistance from sources outside the family boundaries often prevented families from seeking such help. King and colleagues suggested that better understanding of help-seeking may lead to interventions which foster greater utilization of services by family caregivers (King et al., 1995).

Another qualitative nursing study which explored helping, examined the experience of giving and receiving social support by older caregiving couples. Aspects of giving and receiving help between the couples were discovered, but patterns of seeking help were not explored (Schmitt, 1991). A nursing study aimed at understanding barriers to use of community services by caregivers, examined underlying meanings of caregivers’ statements regarding not needing help (Collins, 1992). However, this study like the others, also failed to examine actual patterns of help-seeking. Finally, a first-hand account of help-seeking by a wife with a husband who had multiple sclerosis was written by Cohen (1997). This account provided some insight into the psychosocial process of help-seeking from an insider’s point of view along with strategies to actually get help. The author reported coming to a realization that a crisis was occurring and a recognition that it was not only appropriate to seek help, but also right to do so. Through first-hand accounts of experiences by wife caregivers such as this report, greater understanding of help-seeking patterns can be obtained.

The previously discussed quantitative studies have explored help-seeking as a variable associated with stress, depression, social support, and mental health.

Qualitative studies have explored attitudes toward seeking help from community resources, giving and receiving of help and social support by couples, the meaning of not needing help, and the experience of help-seeking by the wife of a multiple sclerosis victim. No studies however, have explored the actual patterns of help-seeking by family caregivers of demented individuals.

Restructuring of current health care delivery systems has resulted in more emphasis on family responsibility for providing care to chronically ill members. Caring for a family member with dementia can be a difficult challenge for caregivers, resulting in adverse emotional and physical health. If formal support is not provided or accepted by the caregivers, there is a danger that informal caregivers will burn out and become unable to continue caregiving. A strong possibility exists that both the demented individual and the caregiver could require care from health systems when this occurs (Grunfeld, Clossop, McDowell, & Danbrook, 1997).

Decades of studies regarding factors influencing utilization of community services by family caregivers have failed to provide sufficient understanding for explaining underutilization of community services or for health care professionals to design interventions capable of affecting significant changes in utilization patterns. Despite years of research regarding utilization of community services by caregivers of demented individuals, much remains unknown. This researcher believes that reasons for use or non-use of community services must be studied at a more basic level; the level of

patterns of help-seeking. Help-seeking is precursive to any utilization of service. Caregivers must initially recognize that they need help, make decisions to seek help, and then carry out help-seeking activities before any use of services occurs. Help-seeking patterns must first be explored before utilization of specific services can be understood. This study was designed to shed new light on an old problem by exploring help-seeking patterns from the viewpoint of wives caring for husbands with dementia.

Studies exploring help-seeking by family caregivers will become increasingly important as the number of elderly with dementias continues to rise in this country. Ways in which female family members caring for these persons at home can be supported in the caregiving role must be discovered. Long-term care for demented elders is too expensive for many families, therefore when these persons are institutionalized, the economic burden frequently falls on society. From a public, financial perspective, it is essential to discover methods of supporting family caregivers in the caregiving role. As observed by Phillips (1996) "If all families were to refuse to provide care, the public sector would go bankrupt providing for all the long-term care needed by elders in this society" (p. 232).

Purpose

The purpose of this study was to gain an understanding of patterns of help-seeking by older wife caregivers of demented husbands. Interactions, thoughts, and feelings associated with patterns of seeking help were explored using a fluid, grounded theory design, which was modified in response to what was being learned as data were being collected. Wives of demented husbands, who were aged 60 and older, were asked

to describe their experiences associated with actions that they had taken and decisions they had made regarding supportive, assistive, or facilitative services for the purpose of maintaining or sustaining caregiving functions. Understanding obtained from this study provided the basis for a substantive grounded theory of help-seeking by older wife caregivers of demented husbands.

Research Question

The research question guiding this study was: What are the patterns of help-seeking used by older wife caregivers of demented husbands?

Theoretical Framework

The overall theoretical framework for this study was Margaret Newman's Theory of Health as Expanding Consciousness (1979, 1983, 1986, 1994). Within this viewpoint, every person (caregiver) in every situation, is part of the universal process of expanding consciousness, no matter how disordered or hopeless the situation (caregiving) may seem (Newman, 1992). Persons (caregivers) are viewed as "centers of consciousness within an overall pattern of expanding consciousness" (Newman, 1986, p. 24). Consciousness is defined as the "informational capacity of the system (caregivers) to interact with the environment" (Newman, 1986, p. 33), and can be seen in the quality and diversity of interaction between human beings and their environment. The evolution of expanding consciousness is seen in a person's patterns of movement-space-time, and is sometimes smooth, pleasant, and harmonious, and at other times, difficult and disharmonious. Within this theory, expanding consciousness is viewed as a process whereby a person becomes more of oneself, finds greater meaning in life, and

reaches new connectedness with other people and the world in which they live (Newman, 1992).

According to the theory, tension in illness allows patterns of expanding consciousness to emerge. Illness in oneself or family members may serve as a factor that facilitates change in patterns of person-environment interactions that reflect patterns of expanding consciousness (Newman, 1992). Patterns will vary according to the unique configuration of each person-environment situation. However, the Theory of Health as Expanding Consciousness posits that there will be similarity of patterns among persons who share similar medical diagnoses or life experiences (Newman & Moch, 1991). Within this framework, interactive patterns of interpersonal relationships, such as patterns of help-seeking, arising from tensions created by the husband's dementing illness, can be viewed as a manifestation of expanding consciousness.

In view of the lack of knowledge regarding actual patterns of help-seeking by older wife caregivers, a qualitative approach, specifically grounded theory, seemed most appropriate to gaining an understanding of this phenomenon. The qualitative world view holds that it is the interpretation of experience, or human perspective, that constitutes reality. Qualitative research seeks to gain insight into experiences and grasp something of a person's reality (Oiler Boyd, 1993), recognizing that human realities are multiple and complex.

Initially developed by sociologists (Glaser and Strauss, 1967) at the University of California in the 1960s, grounded theory methodology results in the discovery of theory that is grounded in the data obtained from social research. Underlying

assumptions of grounded theory are that people experience shared meanings and experiences (Hutchinson, 1993), and that all of the concepts pertaining to a given phenomenon have not been identified, are conceptually undeveloped, or that relationships between the concepts are poorly understood (Strauss & Corbin, 1990). Grounded theory methodology is particularly useful for the exploration of fundamental social-psychological processes (Chenitz & Swanson, 1986). Since help-seeking has both psychological and social components, grounded theory provided an understanding of these patterns and led to the discovery of an inductively derived theory that was faithful to the reality of the phenomenon under study.

The suitability of grounded theory for exploration of social-psychological processes derives from its philosophical roots in symbolic interactionism. First advanced by Mead (1934), and later elaborated upon by Blumer (1969), symbolic interactionism contends that "humans act and interact on the basis of symbols which have meaning and value for the actors" (Stern, Allen, & Moxely, 1982, p. 203). Within this world view, nothing in the world has intrinsic meaning or inherent value in and of itself. Rather, meaning is created by experience arising from the process of interactions between people and with the self (Blumer, 1969). Symbolic interactionism then, focuses on the meanings of events to people and the symbols that they use to convey that meaning (Baker, Wuest, & Stern, 1992). Learning the meaning and value of these symbols is essential to understanding the psychosocial processes being explored. The researcher seeks, through examination of words, writings, or artifacts, to understand reality as participants understand it, to learn their interpretations and definitions.

Descriptive accounts from participants of how they see objects, act toward them, and refer to them gives insight into meaning. According to Blumer (1969) "One has to get inside the defining process of the actor in order to understand his action" (p. 16).

Using grounded theory method, interviews are transcribed as data and are analyzed to discover relevant categories and the relationships among them. Analysis, data collection, and coding proceed simultaneously with emerging categories determining subsequent data collection until core categories are clearly understood and no negative or contradictory cases are found in the data (Strauss & Corbin, 1990). This circular pattern allows the researcher to change foci and pursue leads discovered during data analysis (Hutchinson, 1993). Using a constant comparative data analysis method, data are categorized on three levels. Theoretical constructs which emerge, together with substantive codes, categories, and their associated properties "form a theory that encompasses as much behavioral variation regarding the phenomenon as possible" (Hutchinson, 1993, p. 200).

Grounded theories which are developed as a result of this process may be formal or substantive. Formal theories address a conceptual level of inquiry. Substantive theories are generated for specific, circumscribed, and empirical areas of inquiry (Hutchinson, 1993). Generation of substantive grounded theory then, was most appropriate for this study which was concerned with a specific group of individuals and circumscribed phenomenon of concern. Grounded theory methodology, based on symbolic interactionism, guided the examination of descriptive accounts from wife caregivers of how they saw help-seeking, how they referred to help-seeking, and how

they acted towards the idea of seeking help. The Theory of Health as Expanding Consciousness provided a perspective for interpreting these accounts, and identifying patterns of interaction, thus providing a framework for development of the emerging theory. Insight gained into the meaning of help-seeking for these women provided the basis for understanding help-seeking and resulted in a substantive theory which was faithful to and illuminated this complex psychosocial phenomenon.

Assumptions

Grounded theory methodology requires the researcher to “make creative use of one’s knowledge and experience while at the same time holding on to the reality of a phenomenon” (Strauss & Corbin, 1990, p. 44). Identification of personal biases that might affect interpretation of data is essential to balance researcher sensitivity with objectivity and assure that the emerging theory is valid, reliable, and truly grounded in the data. Assumptions identified by means of analysis of a bracketing interview as underlying the researcher’s orientation to this study were as follows:

1. Older wives have become accustomed to certain roles in the marital relationship and even when circumstances change, will attempt to maintain normalcy through maintenance of these roles.
2. Caregiving is stressful and exhausting.

3. Caregiver help-seeking precedes service utilization and is a desirable (good) thing.
4. Caregivers place value on privacy, independence, and self-reliance, view seeking help as a weakness, and seek help only as a last resort.
5. Understanding of help-seeking patterns will be useful for nursing practice.
6. There are commonalities and differences in help-seeking patterns across age, racial, and gender groups of caregivers.
7. Women are acculturated to assume caregiving burdens.
8. Help-seeking patterns are affected by family dynamics, change over time, and can be facilitated and modified.
9. Seeking caregiving help for problems of dementia is different from seeking help for other medical problems.
10. Decisions to finally seek help are the result of a personal awareness of the need to change patterns of interacting.
11. Women's perceptions can be barriers for seeking help, requiring them to need permission to seek help.
12. Help-seeking patterns are complex and multidimensional.
13. Experience with caregiving gives one sensitivity to understanding caregiving experiences in others.

Significance

This study was significant in that it was the first study to explore patterns of help-seeking by older wife caregivers of demented husbands. Understanding gained from this study contributes to knowledge regarding help-seeking by wife caregivers of demented husbands and provides a base for future studies. Knowledge gained as a result of this study also has significance for health care delivery systems which provide potential services for demented individuals and their caregivers.

Study findings contribute to the health of women, particularly older ones, because the majority of caregivers of demented individuals are women (Alzheimer's Association, 1996). A study that focuses on older wife caregivers also addresses the needs of a large segment of the caregiver population in this country. Building upon knowledge from the new perspective of psychosocial patterns of help-seeking, rather than the perspective of service utilization, interventions may ultimately be developed which will influence or modify patterns of help-seeking by older wife caregivers, resulting in more effective help-seeking behaviors. More effective help-seeking behaviors will in turn, result in caregivers receiving more assistance and support from both informal and formal sources, reduced stress and burden of the caregiver role, and increased ability to continue in the caregiving role.

An understanding of how and why older wife caregivers seek help and who they seek help from contributes to the base of knowledge necessary for planning service interventions to assist older wife caregivers of the demented in sustaining the caregiving role. As understanding of the dynamics of help-seeking by these women is expanded,

new questions to be explored may arise which will provide direction for future research in this area. Service interventions more compatible with the psychosocial patterns of help-seeking can be designed on the basis of information gained from this study and others like it. Nurses and other health service providers building upon knowledge gained as a result of research in this area can then design delivery of services in ways to make them more acceptable to caregivers.

Delimitations and Limitations

All but one of the wife caregivers in this study were residents of East Tennessee, and therefore, the sample was relatively culturally homogenous. Findings of this study then, are limited to this specific group of caregivers. Since older wife caregivers comprise a substantial portion of the caregiver population, it was appropriate to begin with this group of caregivers. In the future however, help-seeking by other groups of caregivers will also need to be explored. Because data were collected through participant interviews, limitations relating to issues of self-disclosure also pertained to this study. Finally, due to its qualitative, interpretive nature, researcher bias was a potential limitation of this study. Researcher bias was addressed through analysis of a bracketing interview with identification of assumptions and also by participant validation and collaborative verification.

Summary

Family caregivers of demented individuals consistently underutilize available community services even though they suffer from a variety of negative consequences as a result of the burdens and stresses of the prolonged caregiving experience. Despite

years of research and proliferation of community services available for caregivers of demented individuals, service underutilization continues to be a major health care concern. Essential to the understanding of service utilization is an understanding of the more basic patterns of caregiver help-seeking. Help-seeking is precursive to any service utilization, since caregivers must first make decisions to seek help and carry out help-seeking activities before any services are used. However, no reported research has explored help-seeking patterns by these caregivers.

Through use of the Theory of Health as Expanding Consciousness as a guiding framework, and grounded theory methodology, an inductively derived, substantive theory of help-seeking by older wife caregivers of demented husbands emerged from this study. This theory was faithful to and illuminated help-seeking patterns for this group of caregivers. Understanding of patterns of help-seeking by older wife caregivers of demented husbands may lead ultimately to the development of interventions to increase the effectiveness of help-seeking patterns in this large segment of the dementia caregiver population and result in increased use of both informal and formal services, reduced burden and stress of the caregiving experience, and continued ability of caregivers to sustain the caregiving role.

CHAPTER TWO

Review of the Literature

The purpose of this study was to gain an understanding of patterns of help-seeking by older wife caregivers of demented husbands. While wife caregivers are often the primary source of help for elders with dementia living at home, they frequently do not seek or utilize help from formal care services until they are completely overwhelmed by the burden of caregiving. Essential to an understanding of service utilization by family caregivers of demented individuals is an understanding of the more basic process of help-seeking. Exploring interactions, thoughts, and feelings associated with patterns of seeking help by older wife caregivers provided a new perspective and led to a greater understanding of this complex phenomena for a significant portion of family caregivers. The review of literature in this chapter is organized into four sections: (a) the Theory of Health as Expanding Consciousness, (b) effects of caregiving, (c) utilization of community services, and (d) help-seeking perspectives. A summary of the literature review concludes the chapter.

Health as Expanding Consciousness

Margaret Newman's Theory of Health as Expanding Consciousness proposes a view of health as a unidirectional, unitary, process of development (Newman, 1991). In this theory, health is an expansion of consciousness which is characterized by the ability of the person to interact with the environment (Newman, 1979, 1983, 1986, 1994). Disease is viewed as a manifestation of health and a meaningful reflection of the whole.

Disease and non-disease are not separate entities, but are dialectically fused into health as a pattern of the whole. Disruptions in human beings, such as disease or catastrophic life events often become catalysts that potentiate unfolding of life processes that persons are naturally seeking thereby facilitating movement from one pattern of consciousness to another and transformation into order at a higher level, or expanded consciousness (Newman, 1997).

The theory, as described by Newman, has four major components or concepts. These concepts are time, space, movement, and consciousness. Newman further stated that "reconsideration of the original synthesis of health and disease yields a new concept: pattern of the whole" (Newman, 1986, p. 12). This pattern is always moving unidirectionally upward and has fundamental aspects of connectedness, context, and time (Newman, 1987b).

Early nursing studies researching this theory followed a positivist approach as researchers attempted to isolate and manipulate the basic theory concepts of space, time, or movement. Newman (1972) studied the effects of changes in rates of walking on time perception of 52 healthy males, with results of no change in time perception. The relationship between preferred rate of movement and time perception was explored in another study of 90 individuals, with results of significantly longer intervals being perceived as the cadence was decreased (Newman, 1976). Subjective time was also explored by Newman as a developmental phenomena of man's expanding consciousness in a study of 85 elderly subjects which examined the relationship between age, movement, and time perception in these elders (Newman, 1982). Another

study by Engle (1984) supported the relationship between movement, time, and self assessment of health. Finally, a study by Schorr and Schroeder (1991) examined differences in perceived duration of time among 100 volunteers participating in aerobic exercises with resulting decreased perceived duration of time with physical exertion.

Other earlier studies attempted to link psychological conditions with time perception. One study of 65 elderly women supported the hypothesis that depression was related to decreased subjective time (Newman, 1984). Another study explored the relationship between perceived control, age, and duration of time in 40 institutionalized, aged women (Mentzer & Schorr, 1986). In this study perceived duration of time was not found to be significantly related to age or perceived control. The direction of the relationships was reversed from the direction hypothesized, suggesting possible theoretical or methodological problems. Schorr and Schroeder (1989) attempted to demonstrate a relationship between Type A behavior, temporal orientation, and death anxiety using an extension of the Newman Model entitled "Consciousness as a Dissipative Structure". Findings of the study did not support the model.

Newman views research as praxis and visualizes theory, research and practice as one inseparable process (Newman, 1990a, 1990b). The professional nurse is viewed as a therapeutic partner who joins with the client in the search for pattern with its accompanying understanding and impetus for growth (Newman, 1987a). With this idea in mind, a method of pattern identification and research/practice process was developed that was derived from the theory (1990a). Numerous subsequent research studies have employed this methodology for revealing sequential patterns of persons' lives,

facilitating participants' recognition and insight into patterns, and facilitating authentic involvement of the nurse-researcher in the movement toward higher consciousness.

Studies that utilize the Newman theoretical framework and/or methodology and support the catalytic effect of illness or major life problems as a turning point towards more meaningful connectedness and expanding consciousness are plentiful. One such study involved 60 elderly women with chronic illness (Schorr, Farnham, & Ervin, 1991). The predominant health patterns identified in this study indicated that the majority of the women synthesized their chronic illness, diminished functional ability, and decreased control over daily activities into a pattern that reflected expansion of consciousness beyond the physical. Another study of individuals with illness involved 20 women with breast cancer (Moch, 1990). This study found three themes which supported the transformative process of illness and the effects of the illness as a catalyst: (a) changing relatedness, (b) identifying meaning in the experience, and (c) adding new perspectives about life. Similar transformation by women with breast cancer was reported by Roux (1994) who discovered themes of (a) coming to know, (b) strength of she who knows, (c) connection of she who knows, and (d) movement of she who knows. In these two studies the Theory of Health as Expanding Consciousness conceptualized breast cancer as a meaningful part of health for the women.

Further studies supporting expanding consciousness in various illnesses included studies on recognizing patterns in cancer patients (Newman, 1995), life patterns of persons with coronary heart disease (Newman & Moch, 1991), and patterns of persons with chronic obstructive pulmonary disease (Jonsdottir, 1998). Another study

conducted by Lamendola and Newman (1994) found that the experience of HIV/AIDS brought nine gay men to a turning point of more meaningful connectedness. Additional studies applying the theory to ill individuals include a study of health patterning in persons with multiple sclerosis (Gulick & Bugg, 1992) and a study of giving and receiving social support by spouse caregivers and their spouses (Schmitt, 1991).

Newman's methodology process-as-content praxis has been utilized to describe the lived experience of life-passing in middle adolescent females (Shanahan, 1993). Further, Yamashita (1998, 1999) used the theory and methodology to provide a basis for understanding the experiences of Japanese and Canadian primary family caregivers of relatives with schizophrenia. Overall findings supported the premise of Newman's theory of person-environment interaction patterns in that participants were able to identify persons and relationships which formed interaction patterns over time. Also, as a result of pattern viewing, the majority of study participants saw the possibilities for action and decided to act either for themselves or on behalf of their mentally ill relatives. Participants reported cognitive, perceptual, or behavioral changes which were related to care management for the ill relative and indicative of the transformative process of the experience.

A study by Schorr (1993) of 30 women diagnosed with rheumatoid arthritis found that pain perception decreased after the women listened to music suggesting that patterned environmental resonance may have enabled these women to move beyond the pain to a pattern of comfort. Finally, two studies have applied this theory to the study of high-risk pregnant women. Kalb (1990) described the application of pattern recognition

to this group and Schroeder (1993) utilized both quantitative and qualitative approaches to test Newman's proposition that time is a function of movement, that perceived duration of time is an indicator of consciousness, and also to explore the experience of bed rest on women with high risk pregnancies.

Additional literature which focused on nursing practice and the theory included application of the theory to individuals, families, and communities as advocated by Marchione (1986), and three studies of the application of the theory to nursing management at Carondelet St. Mary's (Newman, Lamb, & Michaels, 1991; Ethridge, 1991; Michaels, 1992). Additionally, Gustafson (1990) reported the application of Newman's theory and pattern recognition in doing Parish nursing, and Magen, Gibbon, and Mrozek (1990) reported on implementation of the theory, as one of several theories, in the care of the chronically mentally ill.

The Theory of Health as Expanding Consciousness has also been used in theory development to frame the description of a pinwheel model of bereavement and relevant nursing responses in a study by Solari-Twadell, Bunkers, Wang, and Snyder (1995). This model proposed a framework for assisting nurses to be with the bereaved in a disciplined presence rather than the traditional intervention of "doing something for". The model challenged the accepted notion of "working through" stages of grief.

Newman's theory has also been utilized to provide some of the content for a nursing educational model. This model, called the "Healing Web" was designed to integrate nursing education and nursing service together with private and public

education programs for baccalaureate and associate degree nursing in South Dakota (Bunkers et al., 1992).

The Theory of Health as Expanding Consciousness has provided a basis for research/practice in a variety of clinical settings for diverse client populations, including caregivers. It has been utilized to provide the framework and/or methodology for numerous studies of elders and several studies involving only women. The theory has been used extensively in exploring and understanding the experience of illness in individuals. Findings of experiences of increased connectedness and expanding consciousness have been common in these studies of ill persons, supporting a basic premise of the theory that difficult or crisis situations may provide a catalytic effect and facilitate movement to higher levels of consciousness.

Effects of Caregiving

Caregiving for a family member with dementia is an exhausting experience that impacts every domain of quality of life for the caregiver. Many family caregivers of demented individuals have been engaged in the caregiving experience for an average of four years or more, spending as many as 69 to 100 hours a week in providing care (Alzheimer's Association, 1995). As the dementia progresses, the caregiver is expected to provide physical, social, and emotional care to the demented individual, often alone and on a round-the-clock basis. Literature regarding effects of this prolonged caregiving experience on the quality of life of caregivers will be organized according to impact on the various domains of quality of life.

Physical Well-Being

A consequence of coping with a long, formidable list of care receiver problems is often a prolonged state of fatigue (Wilson, 1989). One study of 51 dementia caregivers reported disruption of nighttime sleep patterns in 16% of caregivers (Gottlieb and Gignac, 1996). Further, a survey of 500 caregivers by the Alzheimer's Association (1996) reported that 45% of the caregivers felt that they were not getting enough sleep because of the demented individual's wandering and wakefulness. It is, therefore, not surprising that caregivers reported being worn out and overwhelmed by the required 24 hour care (Chenoweth & Spencer, 1986; Smallegan, 1985).

Physical effects resulting from prolonged stress of caregiving burden have been reflected in documentation of lower immunity levels in family caregivers of individuals with Alzheimer's disease. Caregivers had lower percentages of total T lymphocytes and helper T lymphocytes as well as higher antibody titers to Epstein-Barr virus than comparison subjects in a study by Kiecolt-Glaser, et al. (1987). In another study by Kiecolt-Glaser and Glaser (1994), spouses of Alzheimer's individuals experienced significantly more days of illness from infectious diseases such as upper respiratory disease and visited physicians more often than matched controls. Additional data on this group of 86 spouses of individuals with Alzheimer's disease and 86 matched controls showed decrements in functional aspects of immunity in the spouse group. A further study which examined caregiver immunity found reductions in natural killer cell activity and elevated sympathetic activity in groups of Alzheimer caregivers and depressed individuals suggesting lower immune response, increased susceptibility to

infectious diseases, and increased neoplastic or autoimmune diseases in both groups (Irwin & Patterson, 1994). These findings were supported by Cacioppo et al. (1998) who also found diminished cellular immune function in 27 wife caregivers of husbands with progressive dementia. Family caregivers then, are vulnerable to a variety of physical illnesses which diminish their capacity to provide care for their demented family members as a result of compromised cellular immunity arising from the stressors of prolonged caregiving.

In further work on physical consequences of caregiver burden, Vitaliano et al. (1994) theorized that caregivers were at very high risk for cardiovascular disease. A cardiovascular disease path model for caregivers developed from a review of studies regarding physical health of caregivers was proposed. The authors hypothesized that the combination of prolonged stress, anger, hostility, and low social support which are associated with the caregiving experience together with the biological risks associated with aging, have the effect of putting caregivers into this high risk category. However, the report did not test the model.

The beneficial effect of formal assistance on caregiver health was documented in a study of 104 caregivers (Domico, 1998). In this study, the majority of caregivers were receiving formal services and 70% of the caregivers reported good or excellent health. All the male caregivers in the study were receiving at least one service and the male caregivers reported better physical health than the females.

In terms of general health, the literature reflects decline in physical well-being over the course of the caregiving experience resulting from physical effects of long term

stress and burden (Haley, Levine, Brown, Berry, & Hughes, 1987; Stone et al., 1987). Exacerbation of physical problems including high blood pressure, disturbances in gastrointestinal functioning extreme weight gain or loss, and generalized fatigue have been reported (Baldwin, 1988). Additionally, exhaustion, heart attack, and disintegration of knee joints and back discs have been noted as results of caregiving burdens (Crossman et al., 1981).

Psychological Well-Being

In addition to the physical effects of caregiving burden, a number of psychological effects have been reported. An important distinction to make when discussing caregiver stress and burden as related to mental health, is the difference between subjective experience of the caregiver's situation and objective demands on the caregiver. This is an important consideration because it is the psychological experience of the objective situation that determines caregiver response to the experience (Dillehay & Sandys, 1990).

In a study of caregiver well-being, George and Gwyther (1986) identified that a majority of caregivers experienced poor mental health. The most common mental health problem reported as a response to the caregiving experience was depression. Seventy-five percent of a group of 500 dementia caregivers reported being depressed occasionally and 34% of this group reported being depressed frequently in a study by the American Alzheimer's Association (1996). Another study of 46 relatives of patients with clinically diagnosed Alzheimer's disease or multi-infarct dementia residing in the community identified that 55% of the major caregivers experienced clinical depression

(Cohen & Eisdorfer, 1988). Finally, a two year longitudinal study of caregivers of elders with dementia reported findings of overall deterioration of psychological well-being as the demented elders' functioning declined and the caregiving continued (Pot, Deeg, & Van Dyck, 1997)

Depression among caregivers is not experienced equally. Gender differences in depression among caregivers were reported in a number of studies (Cohen & Eisdorfer, 1988; Fitting, et al., 1986; Jansson, Graftstrom, & Winblad, 1997). Female caregivers have been identified as having more depression than male caregivers, and in fact, female gender itself was identified as an important risk factor for caregiver strain and distress (Collins & Jones, 1997). However, Schulz and Williamson (1991) found in a two year longitudinal study of depression among Alzheimer's disease caregivers, that female caregivers demonstrated higher constant depression rates while male caregivers showed increasing depression over time.

Gender differences were also found for caregivers of the demented in other psychological areas of well-being such as perceived burden, burnout, and loss of self, with women frequently experiencing more detrimental effects than men. Younger wives and older husbands experienced higher burden (Fitting et al., 1986) and women, particularly wives, experienced more burnout (Almberg, et al., 1997) than other family member caregivers. However, while Kinney and Stephens (1989) found that female caregivers perceived behavioral and cognitive problems with the care receiver to be greater hassles than male caregivers, Ford, Goode, Barrett, Harrell, and Haley (1998)

found no significant differences in caregivers' appraisal of the stressfulness of 44 specific caregiving stressors.

Women caregivers also experienced more loss of self and role engulfment in the caregiving experience than other family caregivers (Skaff & Pearlin, 1992). Additionally, male caregivers reported higher quality of life and purpose and meaning in life than female caregivers in a study by Domico (1998). Finally, female caregivers were found to experience more helplessness and less control over caregiving problems than male caregivers (Batt-Leiba et al., 1998).

Variations in stress and burden among caregivers can be explained to some extent by care receiver characteristics, one of which is care receiver behavior. Disruptive behaviors of the care receiver contributed significantly to distress and burden of the caregiver in one study (Farran, Keane-Hagerty, Tatarowicz, & Scorza, 1993). These findings were supported in another study by Barusch and Spaid (1996) which compared dementia caregivers versus non-dementia caregivers, and reported that memory and behavioral symptoms as well as less marital closeness with the demented spouse contributed to more stress among dementia caregivers. Further, Victoroff, Mack, and Nielson (1998) found that care receiver agitation, particularly physical aggression, was significantly related to caregiver depression and burden in a study of 35 patient-caregiver pairs. Overall, findings have been that the cognitive capacity of the demented individual has less effect on caregiving stress than disruptive behavior and impaired social functioning (Deimling & Bass, 1986).

Racial differences were also found to affect perceived stress and burden of dementia caregivers because beliefs about caregiving influenced whether the caregiving role was perceived as a burden or a satisfying experience. Hispanic caregivers were more stressed and more clinically depressed than their African American or Caucasian counterparts in studies by Cox & Monk (1990, 1993, 1996). Primary sources of stress for this group included not having enough time for self, and high expectations of the demented elder regarding the care that should be given. Compounding the burden on these Hispanic caregivers was a cultural reluctance to share familial problems with outsiders and a hesitancy to admit that the caregiving experience was too demanding. These caregivers were also found to be younger and have less supportive relationships than their black counterparts.

African American caregivers, on the other hand, experienced less perceived burden because of feelings that the extended family integrity was maintained through "kin keeping" and a sense of continuation of family solidarity and continuity (Nkongho & Archbold, 1995). Less stress in African American caregivers was also found in a study which compared them with Caucasian caregivers (Hinrichsen and Ramirez, 1992). However, there are strong expectations in African American families that other family members, particularly other children, should provide assistance or relief to the primary caregivers. Primary caregivers expressed much anger and resentment when these expectations were not met (Fink & Picot, 1995).

The strain of providing care for the demented individual does not only affect the primary caregiver. This burden impacts the entire family unit and may also activate old

family conflicts (Collins, 1992). In a study of 555 caregivers, Semple (1992) found that conflicts of family member's attitudes and actions towards caregivers increased depression in primary caregivers, and conflicts stemming from family attitudes and actions towards the demented patient resulted in increased anger in the primary caregiver.

Surprisingly, some evidence exists that length of time spent in caregiving does not significantly correlate with caregiver stress or burden (Novak & Guest, 1989). In fact, a study by Motenko (1989) suggested adjustment of the caregiver to the experience over time. In this study, caregivers reported less strain and burden after three years or more of caregiving. A further study by Goode, Haley, Roth, and Ford (1998) found no overall declines in caregiver physical or mental health and that worsening of patient stressors were not predictive of individual differences in caregiver functioning. Clark (1997) found mixed results in her study of psychological well-being in 175 caregivers over a one-year period. While the average level of psychological well-being in these caregivers did not decline over the time period, there was a definite tendency towards increased anger and depression in the caregivers who were providing increasing amounts of assistance with instrumental activities of daily living to demented family members. However, another study of 175 demented elderly and their caregivers found overall deterioration of psychological well-being in caregivers who continued to provide care as the elders' cognitive functioning declined (Pot et al., 1997)

Another interesting finding regarding caregiver stress and burden is the fact that the caregiving career, and therefore the stress, does not end with institutionalization of

the family member (Lindgren, 1993). Institutionalization of the demented elder did not decrease caregiver burden, stress, or depression in a number of studies (Collins, Stommel, Wang, & Given, 1994; King, Collins, Givens, & Vredevoogd, 1991; Motenko, 1989). Primary caregivers, particularly spouses, continued to spend time with the demented individual after institutionalization and assumed the additional stress and burden of guilt over the decision to institutionalize as well as concerns over the quality of care being provided for the family member (King et al., 1991). Opposite findings however, were found in a Canadian study by Ross, Rosenthal, and Dawson (1997). In this study although the wives of institutionalized demented husbands still continued to visit frequently, they were more likely to relinquish aspects of caring, express more satisfaction with aspects of institutional care, and report good morale and less depression than wives of non cognitively impaired husbands.

Social Functioning

As the condition of the demented individual deteriorates and the need for care and supervision increases, caregivers experience diminished social functioning. The only social activity that many caregivers seemed to retain was church attendance (George & Gwyther, 1986). Limitations of social life, social isolation, and lack of relationships with friends were frequently cited by caregivers as contributing factors to depression and burnout (Almberg et al., 1997; Brown, 1991; Pratt, Wright, & Schmall, 1987). The role of the caregiver wife has been likened to living "in a social limbo because she does not have a partner with whom to participate in social activities and because she is not free to find another partner" (Brown, 1991, p. 34).

Not only did family caregivers find themselves unable to leave the home to enjoy social activity because of the time and energy spent in caregiving tasks, they often also found that friends and family tended to decrease visits to the caregiver home over time. This narrowing of horizons and decreased informal social support to the caregiver led to feelings of anger, resentment, and perceived increase in burden by the caregiver in studies by Lynch-Sauer(1990) and McCarty (1996). Another finding regarding social effects of caregiving was that more affluent, adult child caregivers, and those responsible for highly dependent elders most often noticed the social constraints of caregiving (Thompson, Futterman, Galleger-Thompson, Rose, & Lovett, 1993).

Cognitive Functioning

While not an effect of the caregiving experience, cognitive functioning of the caregiver has profound implications for health care professionals and society in general. As age, and therefore prevalence of dementia increases, it would be logical to assume that older married couples are at risk for the caregiver to also experience cognitive problems at some point during the long caregiving experience. Rarely are elderly spousal caregivers assessed for cognitive functioning unless obvious deficits are noted by professional caregivers. In a study of 65 married caregiver-demented dyads, 18% of the caregiver spouses had significant, measurable, cognitive impairment (Boucher, Renvall, & Jackson, 1996). More studies of this type are greatly needed.

Loss of Usual Activities

The burden of caregiving for a demented family member frequently consumes all the caregiver's time, requiring them to relinquish other activities that were usual

occurrences, particularly hobbies and recreational activities (Barusch, 1988). Dementia caregivers typically spent less than half the time that their non caregiver counterparts did in hobbies and relaxing (George & Gwyther, 1986). In a sample of 51 caregivers studied by Gottlieb and Gignac (1996), 28% reported that they had to surrender employment, hobbies, and volunteering activities. Another 22% of this sample reported that the dementia deprived them of pleasurable features in their relationships with the demented relative and forced them to abandon future plans for joint travel, recreation, or other mutual pursuits.

Sexual Functioning

While the demented spouse may be physically present, a general theme across caregivers' experiences regarding their relationships and marriages is one of loss. There is a decline from relationships characterized by close companionship to relationships characterized by disorganization, discordance, and loss of intimacy (Blieszner & Shifflet, 1990; Wright, 1991). This decline has been described as a loss of closeness, a gradual loss of mutuality due to the inability to share a common history with the demented spouse (Lynch-Sauer, 1990), disengagement (Barusch & Spaid, 1996), and missing the way the spouse once was (Barusch, 1988).

Caregivers reported that they no longer viewed the demented spouse as the same person who they previously knew and loved (Quayhagen & Quayhagen, 1996). Sexual intimacy often became problematic as perceptions of both the caregiver and the demented spouse changed (Ballard et al., 1997; Wright, 1991). The marriage relationship altered during the caregiving experience to one in which the caregiver

assumed a parenting role (Lynch-Sauer, 1990). Additionally, many caregivers emotionally detached from the demented spouse in order to cope with the frustrations of dealing with difficult behaviors (Chesla, Martinson, & Muwaswes, 1994; Jones & Martinson, 1992).

Life Satisfaction

Caregivers of the demented generally reported lower perceived life satisfaction than comparable groups (Haley, Brown, & Levine, 1987; Cohen & Eisdorfer, 1988; George & Gwyther, 1986). Individual differences in social support and activities have accounted for the greatest amount of variation in decrease in life satisfaction for dementia caregivers (Haley, Levine, Brown, & Bartolucci, 1987). Some sense of life satisfaction, however, was found in the caregiving experience itself. In one study, higher levels of life satisfaction were found in spousal caregivers who did not seek professional assistance in caring for the spouse than those who did, reflecting an acceptance of the caregiving role and positive appraisal of their personal efficacy as caregivers (Colerick & George, 1986).

Financial Impact

The financial burden of caregiving impacted many facets of caregivers' well-being. Caregiving wives were particularly vulnerable for financial burden when dementia affected the breadwinner husband who was then forced to retire before age 65 and thus lost benefits (Brown, 1991). Forty-nine percent of caregivers, in a survey by the Alzheimer's Association (1996) reported making financial sacrifices, such as quitting work or taking time off to provide care for their loved ones. Many caregivers

needed concrete assistance which they could not afford, and many were not eligible for any reduced charge or free service (Haley et al., 1987). In-home help was simply not affordable for many caregivers (Chenoweth & Spencer, 1986). Finally, many caregivers were concerned about whether they would have enough money to care for their own needs as they aged (Alzheimer's Association, 1996).

Summary of Caregiving Effects Literature

The process of caregiving for a family member with dementia impacts every domain of quality of life for dementia caregivers. Often the effects of this prolonged caregiving experience result in decreased quality of life as reflected in decreased physical, psychological, social, and financial well-being, and reduced life satisfaction. Caregivers' relationships with the demented family member undergo profound changes with the caregiver experiencing loss of the loved one, despite the physical presence of that person. A picture emerges from the literature of caregivers who are physically worn out, depressed, socially isolated, financially strained, and physically bound to the home as a result of the caregiving experience.

This study was designed to address a little researched area in caregiving, namely patterns of help seeking by wife caregivers of demented husbands. Knowledge gained as a result of findings of this study provides information for development of interventions to increase appropriate service utilization which will in turn, reduce the stresses and burden of the caregiving experience and lessen the devastating physical, social, and psychological consequences of such stresses and burden. The next section of

this chapter provides a discussion of literature regarding utilization of community services by caregivers of the demented.

Utilization of Community Services

While family caregivers reported a need for assistance (Collins, King, & Kokinakis, 1994; Straw et al., 1991), they chronically underutilized community services. A study by Gwyther (1994) that focused on utilization, found that underutilization dominated the findings with only 25% of 500 dementia family caregivers reporting any use of formal services other than physician visits. The author suggested that there were actually four patterns to caregiver utilization of community services; (a) reluctance to enter formal and/or informal service systems, (b) underutilization of available community-based formal and informal services, (c) delayed utilization, and (d) inappropriate utilization. Since the distinctions between the patterns are somewhat ambiguous, and all of the patterns represent an issue of underutilization, all of the above patterns will be considered as underutilization.

Underutilization findings were consistent across gender of caregivers (Cossette, Levesque, & Laurin, 1995). Underutilization was also consistent across race with differences found only in patterns of underutilization (Cox and Monk, 1990). The review of literature regarding service utilization research is organized according to factors identified as impacting caregivers' decisions to seek and accept community services followed by reports of intervention studies to increase utilization.

Knowledge and Time

Knowledge of available community services did not by itself significantly increase caregiver service usage (Caserta et al., 1987; Collins, Stommel, Given, & King, 1991; Cox & Monk, 1990, 1993; Gonyea & Silverstein, 1991). Specifically, Caserta et al. (1987) found that only half of the caregivers who knew about services utilized even one service. Further, knowledge of services in Alzheimer's support group families predicted only four percent of service use in a study by Gonyea and Silverstein (1991). Caregivers, however, reported a need to receive information regarding such services (Coyne, 1991; Fortinsky & Hathaway, 1990) and expressed dissatisfaction with physicians who did not provide this information to them (Haley et al., 1992).

Time spent in identifying and negotiating appropriate service was a factor limiting formal service utilization. Caregivers exhausted from the burden of caregiving lacked the energy to negotiate the service systems to arrange for care (Collins, 1992). Caregivers reported difficulty locating, obtaining and managing home health aide services (Collins et al., 1994; Liken & King, 1995). Time consideration also limited use of congregate day care. One study found that caregivers actually spent more time in caregiving activities on day care days than on other days, because of extra time required to prepare and transport the demented person to the day care center and also sometimes to coax them to attend (Berry, Zarit, & Rabatin, 1991).

Accessibility, Scheduling, and Cost

Specific services, such as respite care, congregate day care, in-home companion, personal care, and institutional-based overnight services were underutilized or utilized

only episodically by caregivers of the demented elderly (Lawton, et al., 1989a, 1989b, 1991). Accessibility, scheduling, and cost were suggested as possible reasons for this underutilization (Collins & Stommel, 1991; Fortinsky & Hathaway, 1990; Graham, 1989; Lawton et al., 1991).

Accessibility of services was especially limited in rural areas (Fortinsky & Hathaway, 1990; McCabe, Sand, Yeaworth, & Nieveen, 1995). Distance required to transport demented family members for congregate day care services also limited the use of such services (Blume, Persily, Mirones, Swaby-Thorne, & Albury, 1990). Care receiver functional and behavioral criteria by congregate day respite services also limited accessibility for more severely demented individuals (Lawton et al., 1991). Other factors affecting accessibility included scheduling problems and shortage of available hours of service (Lawton et al., 1991).

Cost was another factor impacting utilization of community services (Caserta et al., 1987; Cohen-Mansfield, Besansky, Watson, & Bernhard, 1994; Collins et al., 1994; Haley et al., 1987; Liken & King, 1995; O'Hagen, 1992; Pruchno, 1990). Middle income households utilized fewer services. Both upper and lower household income levels and receipt of Medicaid correlated positively with increased community service utilization (Bass & Noelker, 1987; Hinrichsen & Ramirez, 1992; Stone et al., 1987). In a study by Kelly (1994), black family caregivers who had adequate health coverage and benefits reported no hesitancy in using community services. Other studies however, showed low service utilization even when services were subsidized, suggesting that cost was not as important a barrier to service utilization as supposed (Lawton et al., 1989b;

Montgomery & Borgatta, 1989). Additionally, King et al., (1995) found that caregivers preferred to either pay for formal services or do without rather than incur feelings of indebtedness to relatives or friends.

Care Receiver Needs and Caregiver Characteristics

Increased levels of care receiver needs, such as functional status, age, and cognitive deficit positively correlated with increased formal service usage in a number of studies (Caserta et al., 1987; Gonyea & Silverstein, 1991; McCabe et al., 1995; Wolinsky & Arnold, 1988). However, black caregivers utilized more formal services when the demented family member exhibited increased functional impairment, but not when mental impairment worsened (Cox & Monk, 1990). In contrast, Alzheimer's disease support group attendance was not influenced by care receiver functional impairment in one study (Monahan, Green, & Coleman, 1992).

Caregiver characteristics, such as higher perceived caregiver burden, stress, and depression, were linked to increased service utilization (Bass & Noelker, 1987; Ganzer & Englad, 1994; Lawton et al., 1989b; Monahan et al., 1992; Noelker & Bass, 1989). While Cossette et al. (1995) reported that kinship of the caregiver to care receiver was not a predictor of use of formal services, Pierce, Ader, and Peter (1989) found that employed daughters-in-law, who had other family responsibilities, sought and used formal services more frequently than other family caregivers. Also, O'Hagen (1992) found that husbands were more likely than wives or adult children to use respite services. Caregivers who lived apart from the demented family members were also more likely to utilize community services (Stone et al., 1987), as were caregivers who were

employed or had multiple responsibilities outside the caregiving experience (Collins et al., 1994; McCarty, 1996). Finally, older caregivers utilized more respite care (Lawton, et al., 1989b) and attended Alzheimer's disease support groups more frequently (Monahan et al., 1992) than younger caregivers.

Attitudes, Beliefs, & Values

Caregiver attitudes, beliefs, and values appeared to be an important factor in whether formal services were utilized. Frequently caregivers of the demented preferred to use assistance from family or friends rather than formal services (Collins, 1992; Collins, Stommel, King, and Given, 1991). In a qualitative study of attitudes of 34 dementia caregivers, King et al. (1995) identified four themes affecting utilization: (a) family boundaries govern help seeking, (b) families are owners of difficulties, (c) families are protectors of vulnerable members, and (d) families are self-reliant units. Other common themes in caregiver studies were the desire to remain independent and reluctance to relinquish family control to strangers (Caserta et al., 1987; Gwyther, 1989; King et al., 1995; Liken & King, 1995).

In a qualitative study to develop an understanding of how spouse caregivers constructed their caregiving experience so that they chose to continue providing care, Fitzgibbon (1995) identified a theme of "sustaining philosophy" which referred to an underlying value base which supported and sustained caregivers' commitment to provide care. While caregivers expressed a commitment to continue caregiving, they included statements of conditions under which the caregivers would institutionalize the

spouse. All caregivers in this study identified securing tangible help, both formal and informal, as a necessary strategy to sustain and support the caregiving experience.

Additional attitudes have been identified in other studies as affecting caregiver service utilization. These attitudes included the preferences of caregivers for changing situations by themselves, rather than seeking assistance (Barusch, 1988) and husbands' reports of control over demented wives' care as a crucial issue for them (Harris, 1993). Further, Liken and King (1995) found a lack of perceived suitability or congruence between caregivers and home health aides to be an important issue in service utilization because caregivers wanted people who were more like themselves. This preference for "similar others" was also reported in a study by Pillemer and Suitor (1996) of 254 Alzheimer's disease caregivers. Caregivers were also reluctant to place demented family members in particular day care centers because either social class, cultural level, or racial mix of the day care participants was not congruent with their own (Cohen-Mansfield et al., 1994).

Ethnic and cultural perceptions regarding acceptability of seeking help outside the family system also impact attitude toward community service utilization. In a study involving caregiver use of dementia-specific adult day care centers, only 10% of the 450 study participants were black or minority members (Sherrill, Reifler, & Henry, 1994). Suggested contributors to low service utilization by ethnic minority groups, such as Hispanic caregivers, included expressed cultural reluctance to share familial problems and adherence to norms of filial responsibility to parents (Cox & Monk, 1993). Further, use of professional help was perceived by Hispanic caregivers as failure to assume

proper responsibility for the elder (Cox & Monk, 1990). Finally, across cultures, female spouses often felt obligated to provide exclusive care because of societal role expectations (Brody, 1989; Gwyther, 1988).

Lawton et al (1989b) suggested that enhancement of ego identity in the caregiver role negatively affected attitudes towards service utilization. This ego identity gave a sense of meaning to caregiver's life, enhanced feelings of control, and affirmed a sense of competence in the caregiver. Ego investment in the caregiving role was supported in studies where caregivers were reluctant to utilize formal services because of expressed beliefs that the quality of such care would not be as good as that given by themselves, or concerns for safety of the demented family member when outside caregiver control (Caserta et al., 1987; Collins, 1992; Collins, Stommel, King, & Given, 1991; Miller & Goldman, 1989).

An instrument called the Community Service Attitude Inventory (CSAI) developed by Collins, Stommel, King, and Given (1991) measured caregiver attitudes toward service utilization on five attitude subscales: (a) concern for opinions of others, (b) confidence in the service system, (c) preference for informal care, (d) belief in caregiver independence, and (e) acceptance of government services. These attitude subscales, however, only accounted for 6% of variance in frequency of formal service use and 5% of variance in number of services used in a study of 180 caregivers.

Pedlar (1998) used a revised CSAI with seven subscales in a study of 82 wife caregivers of demented husbands to examine the relationship between attitudes and beliefs and use of community services. Together, the seven subscales of the CSAI

improved the explanatory power of the models developed to explain the use of homemaking services, caregiving services, and the types of community services used. However, the CSAI subscales did not explain the utilization of personal care or transportation services in this study. Low explained variance in the Collins, Stommel, King, and Given (1991) study and the lack of explanatory power for all types of community services in the Pedlar (1998) study suggests that attitudes, by themselves, are not significant predictors of service utilization, or that there were other significant attitudes or issues which were not included in the instrument.

Family Units

Caregiver family units also influenced service utilization. Older, objectively burdened spouses tended to be linked to formal services by active informal networks of secondary family caregivers in a study by Gwyther (1989). Also, family attitudes and support were strong facilitating factors affecting older adult service utilization for mental health problems in a study by Wheeler (1997). Secondary family helpers were important in mediating and brokering services for primary caregivers and freeing primary caregivers so that they could attend more support group sessions in other studies (Bass & Noelker, 1987; Monahan et al., 1992). Further, Gonyea and Silverstein (1991) found that use of community services was increased by presence of a confidant such as another family member.

Intervention Studies

Two studies were found which reported the results, in terms of utilization, of comprehensive interventions to increase caregiver use of community services. The first

study was a report of the Duke in-home respite care model in two rural counties (Gwyther, 1989). Availability, accessibility, financial, and selected ethnic or cultural factors were addressed in this intervention. In-home and overnight nursing home respite care services which were flexible with night and week-end hours were offered. Financial subsidies were also available. Home health workers received specialized training in dementia care and many came from the same ethnic or church background as the family caregivers. A nurse case manager was available. Caregivers who used the program reported positive effects, but only a small portion of the eligible families actually used the services despite the fact that multiple utilization factors were addressed in this intervention. An anecdotal finding was that families might prefer to wait for physician initiated referrals for respite. A significant finding, attributed to the role of the nurse case manager, was that clients who did use the services doubled their use of other appropriate community services within a six month period. This study suggested that favorable initial experiences with formal community services may facilitate seeking of other relevant community services.

A social work intervention to enhance community service utilization was initiated with 193 caregivers of persons with dementia (Weinberger et al., 1993). Individualized service plans based on assessment were used for each caregiver which included recommendations for utilization of services. Social workers called the caregivers within one week after receipt of the plan to assess compliance with the service plan and to resolve any barriers to service use. Letters from the physician were also sent to caregivers reinforcing the importance of complying with the service plan.

When these individuals were compared with a control group of 71 caregivers, the interventions were found to have no significant impact on utilization of community resources.

Summary of Community Service Utilization Literature

From the review of the literature, a complex, multidimensional combination of factors appeared to affect family dementia caregivers' utilization of community services. Knowledge, time, accessibility, scheduling, cost, care receiver needs, caregiver characteristics, attitudes, values, beliefs, and family units all impacted on the decisions of family caregivers of the demented to seek and use formal services. Percentages of explained variances by these identified factors however, have remained disappointing. Also, when these factors were addressed in comprehensive interventions, underutilization of services continued to be a problem. Further study to understand family caregivers' help seeking patterns and their reluctance to utilize available community services continues to be important. In fact, one group of researchers, with extensive experience regarding dementia caregiver service utilization, have suggested as an important area for future research, study of the extent to which service-seeking attempts may be preceded by caregiver appraisals of changes in their physical health, emotional health, and competence (Collins, King, Given, & Given, 1994). This study will explore those issues as they relate to help-seeking and assist in understanding of the basic process of caregiver help-seeking. The following section of this chapter will discuss research regarding help seeking by elderly.

Help-Seeking Perspectives

The majority of help-seeking literature as it relates to the elderly is concerned with help-seeking for mental health related problems. Few studies have explored help-seeking by caregivers of elders. Several different descriptive perspectives have provided the viewpoints for help-seeking studies. Therefore literature relating to help-seeking will be organized according to perspectives which view this phenomenon from psychological, sociological, and nursing viewpoints.

Psychological Perspective

Psychological help-seeking studies examined personality and attitudinal correlates of help-seeking. From this perspective, help-seeking was viewed as it related to mental health concepts such as stress, coping, control, and helplessness. As is common in many studies, demographic characteristics were usually examined as well, but demographic characteristics were not the main focus of the studies.

One study utilizing a psychological viewpoint was a prospective study which obtained measures on mental health status, psychological distress, and stressful life events for elderly individuals preceding the point at which they sought help (Phillips, 1990). This study was designed to explore factors which influenced elderly mental help-seeking. The study compared 120 help seekers to 120 non help seekers. Help-seeking elderly were found to have poorer psychological well-being, more physical health problems, higher levels of unpleasant stressful events, and less perceived social support available when needed. Psychological well-being was the strongest discriminant between the groups of the variables studied. Physical health was the next strongest

discriminator. While stressful events such as bereavement, or social and economic losses were predictors of help-seeking, the elderly frequently delayed seeking help for several months after experiencing the events. Sociodemographic variables were demonstrated to have little ability to discriminate between groups in this study.

Learned helplessness, set in an age-related context, provided the framework for a study by Novak (1987) to explore certain personal mental health variables, responsive to age experience, which might differentiate older individuals who have favorable attitudes towards seeking mental health therapy from those who would not. Variables of control, attributions about cause, self-responsibility, and helplessness deficits, were examined in 113 community dwelling elderly in this study. Self-responsibility for solutions to problems was found to be predictive of positive attitudes toward professional psychological help seeking, while helplessness deficits were predictive of a negative attitude. Also, low-to-moderate sense of personal control as opposed to high or low sense of control was found to be important for personal recognition of need for therapy. Psychological sophistication, or experience and familiarity with mental health therapy, was also positively correlated with positive attitudes towards seeking professional help.

Another study which utilized the psychological viewpoint was a large national study which focused on multiple ways of assessing subjective mental health and the coping techniques people used, including seeking of mental help (Veroff, 1981). Interview data was collected from 1304 women and 960 men ages 21 and over. An elder-specific finding was that older people were more likely than others to deny that

problems were ever too hard to handle. This was called "survival denial" by Veroff. Further findings were that elders were committed to their capacity to cope on their own. Additionally, elders in this study reported a strong commitment to taking care of themselves and feelings of security about their informal sources of support. Findings of this study prompted Veroff to advance a theory of help-seeking with two primary propositions: (a) expectation that something will change as a result of help-seeking is a necessary precursor to help seeking, and (b) an orientation towards the outside world, either people or institutions, that assumes some degree of acceptability of dependence on others is a necessary component to help-seeking. According to this theory, there must be minimal expectation of relief which depends on a person's definition of the source of the problem that allows for the possibility of change. Also, individuals who are too strongly independent or self reliant will likely not seek help.

Perceptions of mental illness symptoms in young and elder participants were studied by Davies, Sieber, and Hunt (1994) to determine if these perceptions could explain differences in help-seeking behaviors between the two groups. Thirty two elders and 44 undergraduate students were given 33 randomly ordered cards with mental health symptoms written on them and asked to sort them according to which belonged together. No differences between the groups was noted in ability to distinguish depression, schizophrenia and normal aging signs and symptoms. Participants were then asked to identify symptoms observed in family members or themselves. Significant differences were noted between groups with the younger participants more likely to label depressive symptomatology. Aging symptoms were observed more frequently by

elders. Study participants were also asked about actions that were taken for the problems. There were no differences between the groups in this respect. Both groups preferred self-help or personal behavior change strategies. The only difference noted between these two groups then, was in observation of mental health symptoms. Specifically, the elderly were less likely to observe depression in themselves or others.

Attitudes and perceptions of elders (n=122) regarding their physicians and how these perceptions affected help-seeking behavior were the focus of another psychological study (Nuttbrock & Kosberg, 1980). Specific research questions for this study were: (a) which medical related attitudes are most important in the help-seeking process, (b) what is the nature of the causal relationship between attitudes and interactions with physicians, and (c) what is the statistical importance of these attitudes as predictors of help-seeking. Age, sex, education, health knowledge, chronic disease, perceived illness susceptibility, and having a regular physician were control variables in the study. Elders' view of physicians as personally interested in them was associated with an expectation, but not actual behavior of seeking medical help. Lack of perception of physician affectivity was strongly associated with the elder not seeking help. In these cases the physician was viewed as a barrier. Surprisingly, perception of the physician as very technically proficient was likely to result in low rather than high utilization of physician services. Perceptions then, in this study, played an important part in decisions of elders to seek help.

The relationship between perceived responsibility both for problems and solutions to problems and help-seeking was examined by Ray et al. (1992) in a sample

of 110 elders. The elders were divided into two groups of 55 each and given vignettes of a situation with symptoms identified as either medical or psychological. They were then asked if they would seek help if faced with the problem and who they would seek help from. The elders were also asked if they would feel responsibility for the problem or solving the problem. Twenty nine percent of the elders who reviewed the medical vignettes assigned self responsibility to themselves and 66% of those who reviewed the psychological vignettes assumed self responsibility. The elders in the psychological group were more inclined to seek help if they appraised themselves as responsible for both having and solving the problem, but would seek help from their social support groups more frequently than from professional help. No relationships were found between appraisal of responsibility and help seeking in the medical group, but they were more inclined to seek physician assistance for problems. The authors emphasized that the vignettes described the symptoms as being problematic and therefore, powerful clues were given that a problem needing treatment existed. This providing of clues possibly accounted for the large percentage (79%) of elderly across groups indicating that they would seek help.

Further exploration of correlations between help-seeking and mental health variables included the study by Zauszniewski (1996). In this study self help and help-seeking among 120 elders were examined as they related to depressive cognitions, adaptive functioning, and life satisfaction. Demographic variables did not correlate significantly with help seeking-behaviors in this study. However, help-seeking for psychological problems was significantly correlated with life satisfaction and the self-

control and self-direction dimensions of learned resourcefulness. Elders high in both self help and help-seeking scored highest in absence of depression, adaptive functioning, and life satisfaction. The authors concluded that healthy elders may benefit from interventions which facilitate self help and teach them to seek outside help.

Gwyther (1990) applied the psychosocial hypothesis of separation-individuation to analyze themes in a case study of a wife caregiver of an Alzheimer's husband. Using this perspective, Gwyther stated that separation-individuation conflict occurred within the dyadic relationship between the wife caregiver and demented spouse as the wife balanced her longing for "we-ness" fulfillment with new needs for separate boundaries and new definitions of herself as protective kin or decision maker. Separation or letting go began when the wife was faced with making decisions and judgements without guidance, input, or support from the impaired husband and finally was forced to seek outside help from family or formal services. Gwyther further hypothesized that asking for help by this wife was an acknowledgment of loss of the "we-ness" and suggested that such wives may need permission or guidance to share care and seek help.

Sociological Perspective

When viewed from a sociological perspective, help-seeking is seen as a socially mediated process. Influences of social networks, social interactions, social class, education, and gender on help seeking are explored. Sociodemographic characteristics are of major importance when this viewpoint is utilized.

An intervention study by Robinson and Yates (1994) explored the effects of two caregiver training programs on burden and attitude toward asking for help. In this study,

33 caregivers were randomly assigned to either a social skills development program (SSDP), a behavioral skills management program (BSMP) or a control group. The SSDP taught caregivers how to develop ties and form new connections. The BSMP taught skills and techniques to help the caregiver manage and cope with the demented individual. Participants in the treatment groups were also given the opportunity to participate in both types of training programs. There were no significant differences noted between the treatment groups and the control group pre and post test on measures of attitudes of asking for help or using adult day care. However, participants who received both types of training programs demonstrated significantly higher (more positive) attitudes towards both asking for help and using adult day care ($p < .001$) demonstrating the importance of both components towards attitudes regarding the use of help.

Using the sociological perspective, help-seeking behavior as a form of coping within the larger context of community networks was examined by Pilarzyk (1986) in a study of 592 cosmopolitan neighborhood dwellers which included elders. Three models of communities; fragmented, specialized, and dispersed, represented the ecological, social status, and intimate network factors operational in neighborhood integration and help seeking behavior. Choice of seeking help from others was best predicted by characteristics of residents' intimate networks followed by status variables. The size of the cosmopolites' intimate networks was the most consistent predictor of using help seeking. Residents who had large accessible intimate networks tended to use natural helpers for personal problems while those with larger neighborhood networks tended to

use formal services more. However, members of intimate networks were also found to be referents for formal help. The informal networks, then, acted both as resources for help and referents for professional services in this study.

Sociodemographic characteristics which distinguished those elderly who sought professional home care from those who did not, were examined in 450 elderly in the Netherlands (Fredricks et al., 1992). A model of predisposing, enabling, and need factors developed by Anderson (1975) was used as a framework for this study. Analysis revealed that home care seekers were more often female, not married, and living alone. Additionally, help seekers had less extensive social networks, received less informal care, received fewer visits from family or friends, had more mental problems, were more handicapped, and had insufficient financial means. When logistic regression analysis was done to control for dependencies, only two characteristics were significant; handicap, and amount of informal care received. The authors however, stated that the fit of the model to this data set was not satisfactory. Conclusions were that some important discriminatory factors may have been omitted from the study. A suggestion was made that qualitative research might lead to new clues and testable hypotheses.

A study which combined sociological and psychological viewpoints was conducted by Husaini, Moore, and Cain (1994). Help-seeking behavior for emotional problems in the elderly and the extent to which race, gender, and presence of psychological symptoms affected help-seeking behavior and utilization of formal and informal resources was examined in this study of 500 black and 500 white elders. Respondents were asked what they typically did and to whom they turned for help when

they were really upset or experienced emotional problems. Self-help and religious strategies were found to be dominant in both groups. Use of clergy was higher among the black elderly group, especially among black females who were also more likely to pray when they experienced problems. Both groups sought help equally from informal support networks. Less than six percent from each group sought help from professional services, and these individuals were likely to be more depressed or have a psychiatric diagnosis. The most frequent self-help response across the groups was prayer followed by a "wait and hope" attitude.

Another sociological study examined the degree to which formal help-seeking might be related to diminished network resources in a group of Jewish elders living in Jerusalem (Auslander & Litwin, 1990). The social networks of 100 elderly first applying for public social welfare services were compared to the networks of 100 elders who had not applied for services. The applicant sample was older, more likely to be unmarried or widowed, had higher levels of functional disability and lower levels of physical capacity than the comparison group. Additionally, the overall size of the close networks of applicants was an average of two persons smaller and the distant networks were also smaller than those of the comparison group. Finally, while the average frequency of contacts with network members and duration of network ties was similar for both groups, the applicant sample reported lower perceived affective or emotional support from their networks. Differences in age, network configurations, perceived affective support and physical capacity then, were discriminators between the two groups.

Sociological research aimed at determining characteristics of elderly patients seeking help at a psychiatric emergency room (PER) was conducted by Puryear, Lovitt, and Miller (1991). This study described the characteristic of 118 elderly patients who were seen in the PER during a one-year period. The typical patient seen in the PER was an unemployed or retired female with eight to twelve years of education. Over ½ of the patients had a history of psychiatric illness and the most common presenting complaint was peculiar or disturbing behavior. Most of the complaints were of six months or greater duration. Many of the elders seen in the PER lived with their families and were brought in to the PER by supportive family members who were seeking help in caring for the patient. The caregivers brought the family member in when they were “at the end of their rope”. The majority of elderly persons seen in the ER then, were most likely to be brought in by families when a chronic process created sufficient problems to cause substantial disturbance in the family members caring for them.

The relationship between social resourcefulness and dementia caregiver well-being was examined in a study of 65 caregivers (Rapp et al., 1998). In this study, “social resourcefulness” referred to covert and overt behaviors persons employed to request, direct, and maintain helpful behaviors by other persons. Social resourcefulness as defined was positively correlated with larger social networks, higher social support, better perceived health, increased quality of life, lower depression and greater perceived benefits from the caregiver role.

Finally, a descriptive exploratory study design was employed by Knisely and Northouse (1994) to study the relationships between the level of social support, level of

psychological distress, and extent of help-seeking in a group of 53 hospitalized psychiatric patients aged 18 to 81. Levels of the individual's social support and psychological distress were not related in this study, nor were levels of psychological distress and help seeking behavior. However, help seeking was highly related to the individual's perceptions of their social support. The authors concluded that individuals attempt to use social support networks to the extent that they perceive those networks being available and responsive.

Nursing Perspective

The nursing perspective allows for a more holistic view of the process of help-seeking. The person-health-environment components of the help-seeking process can be viewed as a whole, rather than as fragments, when utilizing this world view. The only studies which explored lived experiences of individuals seeking help were nursing studies.

Two nursing qualitative studies regarding elder help-seeking utilized nursing theory to guide the studies and interpret the findings. In one study, Livingston (1991) utilized a qualitative descriptive approach and Rogers' Theory of Unitary Human Beings to study life experiences of three wives of elderly alcohol abusers who sought professional help for the first time. Past life experiences leading to the choice to seek help as well as life experiences after the first help seeking attempt were explored. Three themes including problematic marital interactions, significant event, and lack of mutuality were extracted which described mutual interactions between the wife and elderly alcohol abusing husband that gave rise to seeking professional help for the first

time. Themes of shame and isolation, and loss of control were extracted which described thoughts and emotions which surrounded the choice to get help for the first time. Two additional themes were extracted which described the repatterning of the life experience of the wife after the first professional help-seeking. These themes were "increased awareness" and "will seek professional help again". First help seeking attempts by these wives then, were a problem-solving approach to a problematic marriage, characterized by lack of mutuality in interactions, leading to feelings of isolation and shame which evolved over time into a significant event, which meant loss of control. The first professional help experience led to an increased awareness by the wife and decisions to seek help again. Viewed within the theoretical framework of Unitary Human Beings, help-seeking was viewed as an attempt to repattern the wives' experiences with their alcoholic husbands.

Schmitt (1991) explored the experience of giving and receiving social support in a qualitative study involving 20 caregiving couples utilizing the framework of Margaret Newman's Theory of Health as Expanding Consciousness. Specific questions were asked about the helping situation regarding the meaning of help, feelings about help, problems with helping, and who does the helping. Three categories of themes emerged; helping, relationships, and outlook on life. Helping themes that emerged were: (a) adjusting roles, (b) meaningful help, (c) better giving than receiving, (d) difficulties related to helping, (e) helping is part of marriage, and (f) helpers are good people. Couples reported the most difficult part was asking for help. Reasons given for this difficulty included striving for independent accomplishments, avoiding indebtedness,

perceived inadequacy, and avoiding imposition on the helper. Viewed within the theoretical framework of Health as Expanding Consciousness, health for the couples was the process of developing awareness of themselves and their environments, and increasing their ability to perceive alternatives such as help and respond in a variety of ways.

A grounded theory nursing study by Szabo (1997) that explored the experience of control as perceived by family caregivers of demented individuals found that help-seeking was an important property of both main themes of "maintaining control" and "lacking control". Caregivers who were able to maintain control and thus manage the stresses of the caregiving situation were able to recognize the need for and ask for help. However, caregivers who were unable to cope with the caregiving demonstrated an inability to recognize the need for or ask for help. These caregivers were often unable to articulate what help they needed or how others could help. This study supports the importance of help-seeking and the need to study this important component of successful caregiver adaptation and continuation.

A study examining family conflicts around dementia home care described help-seeking with families of demented individuals (Davis, 1997). This qualitative study of 35 caregivers discovered that when primary caregivers sought help from other family members, conflicts arose over situations of substantive, complimentary, or cojoint caregiving. Many primary caregivers in this study were reluctant to ask other family members to substitute either because of their belief or the belief of other family members that one family member must assume primary care responsibility or the

concern that no one else could provide the desired quality of care. Complementary caregiving, in which indirect caregiving activities such as running errands or performing home maintenance chores were requested of family members caused fewer family conflicts. Cojoint caregiving which required family members to collaborate with the primary caregivers to provide caregiving was often associated with conflict over other family members' discomfort with the demented persons' behaviors and problems. Many primary caregivers in this study reported anger, depression, and discontinuance of requests for family assistance when faced with avoidance behaviors of other family members. While, not focusing specifically on patterns of help-seeking, this study sheds light on help-seeking patterns within family units.

Finally, Cohen (1997) described her own experiences in help-seeking as a wife of a husband with multiple sclerosis. Descriptions of how she arrived at the decision to seek help and how she went about getting help were included in the account of her experiences. Cohen's lived experience included first coming to a realization that a crisis existed and that it was her right to ask for help and gather a support system. She stated that a commitment to asking for help was also a commitment to fulfill a person's responsibility towards the ill person who also has a right to more help. Strategies employed to get help included writing asking-for-help letters to relatives, calling family meetings, and networking to gather community support and assistance. She concluded with a statement that asking for help makes one vulnerable and requires a special brand of assertiveness, but asking for help can be a vehicle which drives the crisis towards eventual resolution.

Summary of Help-Seeking Perspectives Literature

The majority of literature which pertains to help-seeking by elders is from the psychological or social science areas and seeks to explain help-seeking for elder mental health problems. Rather than exploring patterns of help-seeking, these studies attempted to differentiate help seekers from non help seekers, characterize help seekers, or predict individuals who will seek help. Variables, such as sociodemographics, perceptions of physicians affectivity, level of physical illness, or psychological distress, size of support networks, social skills, and perceptions of responsibility have all been related to whether a person seeks help or not. Universally, elders appear to prefer to seek help from informal support networks rather than professional providers.

Within the nursing literature, studies are noted with a different perspective: one that is consistent with that of theory-based nursing practice. Concern for the person as a holistic being is evident in these studies which seek to understand the caregiving experience holistically including feelings, and thoughts associated with patterns of help-seeking and the meaning of the experience rather than isolated behaviors.

Summary

Caregivers of family members are impacted negatively in almost every domain of functioning by the prolonged caregiving experience. They report physical exhaustion, decreased physical health, depression, social isolation, decreased life satisfaction, unfulfilling relationships, and financial strain as results of the caregiving experience. Despite all these negative effects, caregivers, the majority of whom are women, chronically underutilize available community services which might lessen the burdens

of caregiving. Knowledge, time, accessibility, scheduling, care receiver needs, caregiver characteristics, attitudes, values, beliefs, and family units have all been found to impact caregiver decisions to seek and utilize formal services. Although some intervention studies have been done, they failed to significantly increase caregiver service utilization. Also, adequate amounts of variance in utilization have not been explained with multivariate models.

Knowledge of help-seeking is important to the development of effective interventions. An understanding of help-seeking patterns precursive to service utilization will provide a missing piece of the puzzle, however research in this area is limited. The majority of help-seeking studies in elderly samples have focused on psychological and sociological perspectives differentiating help seekers from non help seekers, predicting individuals who would seek help and describing characteristics of those who do seek help. Little research exists which explored actual patterns of seeking help with accompanying thoughts and feeling associated with this experience. Only nursing literature has viewed the help-seeking process from this perspective. Viewing help-seeking within a holistic nursing perspective provides a means to illuminate and gain some understanding of this complex process. This study explored patterns of help-seeking in wife caregivers of husbands with dementia, extending the existing body of knowledge regarding this basic process, and providing information that will be useful in development of more effective interventions. Interventions based on this new knowledge will increase caregivers' utilization of community services, reduce caregiver stress and burden, and increase caregivers' ability to sustain the caregiving role.

CHAPTER THREE

Methodology

The purpose of this study was to gain an understanding of patterns of help-seeking by older wife caregivers of demented husbands. The process of help-seeking by wife caregivers is poorly understood and there are no existing theories that adequately explain the phenomenon. Therefore a qualitative approach, specifically grounded theory, was utilized in this study, together with an a priori theoretical framework of Newman's Theory of Health as Expanding Consciousness (1979, 1983, 1986, 1994). Newman's theory provided a perspective for interpreting the experiences of wife caregivers and identifying patterns of interactions, thus providing a framework for the development of the emerging theory.

Within the framework of the Theory of Health as Expanding Consciousness caregivers are viewed as "centers of consciousness within an overall pattern of expanding consciousness" (Newman, 1986, p. 24). Consciousness is defined as the "informational capacity of the system (caregivers) to interact with the environment (Newman, 1986, p. 33), and can be seen in the quality and diversity of interactions between human beings and their environment.

The evolution of expanding consciousness is seen in a person's patterns of movement-space-time, and is sometimes smooth, pleasant, and harmonious, and at other times difficult and disharmonious. The process of expanding consciousness is viewed as a process whereby a person becomes more of oneself, finds greater meaning in life, and

reaches new heights of connectedness with other people and the world in which they live (Newman, 1992). Health is the process of “developing awareness of self and environment together with increasing ability to perceive alternatives and respond in a variety of ways “ (Newman, 1983, p. 164). Interactive patterns of interpersonal relationships, including the process of help-seeking were viewed as a manifestation of expanding consciousness within this theoretical framework. This viewpoint allowed insight into older wife caregivers’ experiences, including interactions, thoughts, and feelings associated with help-seeking, providing a new perspective and understanding of this process.

Through use of grounded theory methodology, an inductively derived substantive grounded theory emerged which was faithful to and illuminated patterns of help-seeking for this group of caregivers. This chapter discusses the study methodology including the following areas: (a) underlying philosophical basis for grounded theory: symbolic interactionism (b) description of grounded theory, (c) theoretical sensitivity in grounded theory, (d) sampling methodology, (e) data collection methods, (f) data coding and analysis methods, and (g) verification.

Symbolic Interactionism

Grounded theory is philosophically based on symbolic interactionism. The foundations for symbolic interactionism were laid by George Herbert Mead (1934) and later expanded and elaborated upon by Blumer (1969). Symbolic interactionism contends that “humans act and interact on the basis of symbols which have meaning and

value for the actors” (Stern et al., 1982, p. 203). Blumer proposed three premises as the basis for symbolic interactionism:

1. Human beings act toward things on the basis of meanings that the things have for them.
2. The meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows.
3. These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters
(Blumer, 1969, p. 2).

Symbolic interactionism is also grounded on a number of “root images” which represent a specific viewpoint of human society and conduct. These “root images” are:

1. Human groups are seen as consisting of human beings who are engaging in action.
2. The activities of the members occur predominantly in response to one another or in relation to one another.
3. Worlds that exist for human beings and for their groups are composed of “objects” and... these objects are the product of symbolic interaction.
4. The human being is seen as an organism that not only responds to others on the non-symbolic level but as one that makes indications to others and interprets their indications.

5. The human individual confronts a world that he must interpret in order to act instead of an environment to which he responds because of his organization.
6. Human group life consists of, and exists in, the fitting of lines of action to each other by the members of the group (Blumer, 1969, pp. 6-17).

According to symbolic interactionism, nothing in the world has intrinsic meaning or inherent value except as created by experiences arising from the process of interactions between people and with the self (Blumer, 1969). Thus, meanings are viewed as social products. The role of meaning in the formation of behavior is paramount. It is only through understanding the meanings of events to people and the symbols that they use to convey that meaning that one can come to understand behavior.

Learning the meanings and values of these symbols then, is essential to the understanding of psychosocial processes such as help-seeking. Through examination of descriptive accounts from participants of how they see objects, act toward them, and refer to them, researchers gain insight into meaning by learning interpretations and definitions. Words, writings, or artifacts may all provide insights into reality as participants understand it and assist the researcher to “get inside the defining process of the actor in order to understand his action” (Blumer, 1969, p. 16). Exploring and understanding meanings in symbolic interactionism then, requires a method that views actions from the perspective of whoever is performing the action. Grounded theory is such a method.

Grounded Theory Description

Grounded theory method is a qualitative approach developed by Glaser and Strauss (1967) which has two underlying assumptions:

1. . . . People experience shared meanings and experiences (Hutchinson, 1993)
2. . . . All of the concepts pertaining to a given phenomenon have not yet been identified, relationships between the concepts are poorly understood, or the concepts are conceptually undeveloped (Strauss & Corbin, 1990).

Grounded theory adds another component to the description of experience which is common in other qualitative approaches, by providing an understanding of the process by which experience happens (Artinian, 1998). This approach then, seeks to discover a new theory that is inductively derived from the study of the phenomenon it represents through examination of interactions and the meanings of those interactions for people. Grounded theory methodology provides the framework for taking observations, intuitions, and understandings to a conceptual level, and also provides guidelines for the discovery and formulation of theory (Orona, 1997). The theory is grounded in reality as experienced by participants. Since this method was developed by sociologists for the purpose of “discovery of theory from data systematically obtained from social research” (Glaser & Strauss, 1967, p. 2), it is particularly useful for the understanding of fundamental social-psychological patterns (Chenitz & Swanson, 1986), such as help-seeking.

Grounded theory methodology begins with an area of study and then what is relevant to that area is allowed to emerge. Using this methodology, interviews are

transcribed as data and analyzed to discover relevant categories and the relationships among them. Hypotheses proposing relationships among concepts are systematically derived from the actual data relating to the phenomenon under study. Research begins with a broad view and becomes progressively narrower and more focused as concepts and relationships are discovered. Data collection, analysis, and coding proceed simultaneously with emerging categories determining subsequent data collection.

Through a constant comparative method which will be described in more detail in the section on coding and analysis, concepts and relationships are both generated and provisionally tested. Comparisons sensitize the researcher, enabling recognition of potential categories and identification of relevant conditions and consequences which appear in the data. Each incident identified from data is compared with previous incidents in the same and different groups of the same category which in turn generates the theoretical properties of the category (Glaser & Strauss, 1967). This results in a theory that “is derived from data and then illustrated by characteristic examples of data” (Glaser & Strauss, 1967, p. 5). The theory that is generated is faithful to everyday reality.

Theoretical Sensitivity

Theoretical sensitivity is an essential component for doing grounded theory. It refers to a “personal quality of the researcher that indicates an awareness of the subtleties of meaning in data”(Strauss & Corbin, 1990, p. 41). It encompasses qualities such as having insight, the ability to give meaning to data, the capacity to understand the data, and the ability to separate what is pertinent from what is not (Glaser, 1978).

Theoretical sensitivity may be derived from several sources including professional experience, personal experience, literature, and the analytic process of interacting with the data.

Theoretical sensitivity implies an openness to the data free from preconceived ideas regarding the phenomenon under study, but not an ignorance of the phenomenon. It requires the creative use of one's knowledge and experience while at the same time maintaining the reality of the phenomenon (Strauss & Corbin, 1990). An attitude of skepticism is always necessary and validation of creatively generated categories and statements of relationships is essential. Through use of theoretical sensitivity, the researcher utilizes self as an instrument to creatively name categories, make free associations necessary for generation of questions, and make comparisons which lead to discovery. This sensitivity "enables the analyst to see the research situation and its associated data in new ways and explore the data's potential for developing theory" (Strauss & Corbin, 1990, p. 44).

The researcher-as-instrument in this grounded theory study is a 53 year-old female nurse who is a doctoral candidate in the College of Nursing at the University of Tennessee, Knoxville. Theoretical sensitivity was developed in this researcher through years of professional and personal experiences and familiarity with literature.

Professional experiences can provide the researcher with a rich knowledge base from which to draw insights. However, Strauss and Corbin (1990) caution that this kind of experience can block one from seeing what has become routine or obvious. In this researcher's professional practice as a gerontology nurse and as an educator she has

witnessed the impact of prolonged caregiving on family caregivers who, finally unable to cope with caregiving demands, have reluctantly institutionalized the demented individual. Often, physical or mental collapse of the primary caregiver precipitated the decision to institutionalize. Many of these caregivers sought no help from available community services prior to deciding to institutionalize the demented elder. When queried about knowledge regarding available services, many caregivers reported that they knew about services, but did not use them. Questions regarding why these caregivers did not seek help earlier began to trouble this researcher.

Personal experience can contribute to providing a basis for making comparisons and contribute to sensitivity, but the researcher must be careful not to assume that her experiences are similar to those of everyone else (Strauss & Corbin, 1990). Personally, the researcher's 83 year-old father had multi-infarct dementia and was being cared for by the researcher's 78 year-old mother. Despite many suggestions by the researcher and other siblings that the mother explore available community services, the mother would not even participate in a local Alzheimer's support group. Further, the mother would not ask or accept offers from the children to stay with the father so that she could get away for short periods of time. The mother suffered a myocardial infarct during the caregiving experience. However, despite residual heart damage, she continued to shoulder the responsibility for supervision and care required by the demented husband and considered seeking assistance only shortly before the death of the husband, and only because of increased need for physical care. This personal experience has provided

further impetus for this researcher to gain understanding of the help-seeking process of caregiving wives of demented husbands.

Further theoretical sensitivity arose from the researcher's personal experiences with caregiving for her husband for approximately 10 months prior to his death from complications of systemic diffuse scleroderma and renal failure in January of 1999. While the researcher's husband remained mentally competent throughout his illness, first hand experience with caregiving and help-seeking contributed to an understanding of these concepts on a level that otherwise would not have been possible. Also, because of the researcher's personal caregiving experiences, empathic connections between participants and researcher based upon shared experiences occurred. That is, the researcher was able to interact with participants and "read the silences" through reflecting and sharing of perceptions based upon a personal understanding of the experience. Comments by the wife caregivers such as "You really understand what I am talking about" were common.

Literature can stimulate theoretical sensitivity by providing concepts and relationships to examine against actual data (Strauss & Corbin, 1990). Literature has provoked much questioning in this researcher. In addition to the Ph.D. in nursing at the University of Tennessee, this researcher completed a minor in gerontology, and during the course of studies had read much literature related to caregiving, caregiver burden, utilization of community resources by caregivers, and help-seeking by caregivers and elderly. Despite the large body of knowledge in these areas, the actual process of help-seeking by family caregivers of demented elderly has been largely unexplored.

Caregivers had rarely been asked directly about their experiences, thoughts, and feelings, regarding seeking help in caring for the demented family member, thus the researcher's questions regarding the help-seeking process of caregivers remained unanswered. So, the research question was developed to explore the experiences of wife caregivers of demented husbands in order to gain an understanding of the complex process of help-seeking. In view of the dearth of knowledge regarding this subject, qualitative research methodology was selected.

During the process of analyzing data gathered during this study this researcher gained additional theoretical sensitivity. Further insight and understanding of help-seeking was gained as the researcher gathered, categorized, and interacted with the data. This increased sensitivity to concepts, their meanings, and relationships made it necessary to interweave data selection with data analysis because each fed into the other (Strauss & Corbin, 1990). Analytic sensitivity together with the theoretical sensitivity gained from professional and personal experiences, assisted this researcher to approach the research situation with openness, questioning, and creativity.

While theoretical sensitivity is important, it is equally important that theoretical sensitivity be balanced by reality and that researcher bias not affect interpretation of data. A bracketing interview was conducted and analyzed prior to data collection in order to identify researcher assumptions regarding the phenomena of study. Cross-checking of participants' stories, critical self-reflection of the researcher's perceptions, memoing, log keeping, and content verification was also utilized to minimize researcher bias. Additionally, Strauss and Corbin (1990) suggest three methods for assuring that

the reality of the phenomenon is maintained: (a) periodically stepping back and asking questions such as "What is going on here?" and "Does what I think I see fit the reality of the data?" (p.44), (b) maintaining an attitude of skepticism, and (c) following the research procedures. Use of these methods all assured that the emerging theory was truly grounded in the data and was valid and reliable.

Sampling Methodology

Eligibility criteria for participant inclusion in this study were: (a) Caucasian wife of husband with a diagnosis of non-AIDS related dementia, (b) primary caregiver of the demented individual in the home, (c) ability to speak English, (d) age 60 or older, and (e) no cognitive impairment. The nonprobability sample of older wife caregivers was accessed through adult day care centers, physician's offices, home health agencies, geriatric screening services, Alzheimer's Associations, senior centers, and churches in East Tennessee. Husbands of study participants had to have a diagnosis of dementia by a primary care provider.

Two methods of participant recruitment were utilized. First, notices explaining the study and providing telephone contact information were posted by the primary researcher in the above mentioned sites. When potential participants contacted the researcher via telephone, the researcher explained the study to the potential participant. If the potential participant agreed to participate, an interview was scheduled at a time and site convenient for the participant. Secondly, key personnel at the above mentioned sites were asked to inform potential participants of the study and provide them with an Introduction to the Study letter (see Appendix A). If potential subjects expressed an

interest in participating in the study, they were asked to sign a Consent to Release Name/Telephone Number form (see Appendix B) which authorized site personnel to release this information to the researcher. These potential participants were contacted by the researcher via telephone and the study was explained to them. If they agreed to participate in the study, an interview was scheduled at a time and site convenient for them.

Interview sessions consisted of completion of a demographic questionnaire (see Appendix C) and the qualitative interview focusing on help-seeking, followed by additional questions (see Appendix D) to capture contextual information which may not have been covered in the interview. Cognitive ability of the wife caregiver was determined by the researcher when demographic information was requested prior to the qualitative interview. The demographic questionnaire included questions which could be used to assess recall, memory, and the ability to calculate, corresponding to components of the Mini Mental State Examination (MMSE) which is routinely used to evaluate cognition in elders (Folstein, Folstein, & McHugh, 1975). Additional questions were utilized to determine orientation if deemed necessary.

Participant rights and confidentiality were protected according to Federal law as implemented by the University of Tennessee guidelines. Participation was voluntary with no consequences to participants for failure to participate in the study or for withdrawal from the study. There was minimal risk to participants in the study. The interview had the potential to evoke emotional reactions which some participants could find distressing. The nurse researcher, who has over 30 years of nursing experience,

provided intervention support, counseling, and necessary referrals in these situations. Participants benefited from being able to discuss their experiences with the researcher and from gaining insights in recognizing their interaction patterns. As an additional benefit of participation in the study, caregivers received a resource directory such as the Service Directory for Older Citizens (Knoxville-Knox County Office on Aging, 1998) listing and explaining resources available in the county in which the caregiver or care receiver resided. This directory was given to participating caregivers and the contents were discussed after the interview.

Verbal and written explanation of the study was provided prior to obtaining consent, and a copy of the explanation and consent was given to participants along with researcher contact information. Signed consents (see Appendix E) were obtained prior to beginning the first interview. Names of participants were known only to the researcher, and all data was stored in a secure manner. All interviews were audio taped and audiotapes were destroyed after transcription and verification. Only code numbers appeared on transcriptions. Additionally, approval of the Institutional Review Board (IRB) was obtained prior to commencement of the study (see Appendix F). Consistent with the research design, sample size was determined by the emerging theory and sample selection continued until theoretical saturation occurred. While saturation seemed evident after the seventh participant interview, sampling continued through participant number eleven to verify that saturation had been reached and to assure richness in the development of all categories.

A specific type of sampling utilized in grounded theory is theoretical sampling. Theoretical sampling involves "sampling on the basis of concepts that have proven theoretical relevance to the evolving theory" (Strauss & Corbin, 1990, p. 179). This type of sampling, involves events or incidents that are indicators of categories, their properties and dimensions, not persons per se, in order to develop and conceptually relate them. The sampling was cumulative and increased in depth of focus as the research progressed. Sampling was directed by the logic and purposes of the three types of coding procedures utilized in grounded theory and also by theoretical sensitivity. Sampling, data collection, coding, and analysis occurred simultaneously in a circular process which was continuously refined as theory emerged. During initial data gathering, sampling had little structure and was open to all possibilities for the purpose of uncovering as many potentially relevant categories with accompanying properties and dimensions as possible. Study participants were asked to "Tell me about a time that you felt you could have used help in managing care for your husband". While actually interviewing and observing, the researcher was adjusting interviewing and observation according to analytic sensitivity on site. Questions became more focused as the interview progressed in order to achieve richness and completeness of the phenomena description and fully develop the theory.

As concepts, categories, properties, and dimensions emerged, sampling became relational and variational, focusing on uncovering and validating relationships. Questions became more focused. The researcher attempted to find as many differences as possible at the dimensional level of the data through questioning and comparing.

Sampling became even more directed and deliberate as the theory continued to emerge. Persons, and incidents were selected that maximized opportunities for verifying the core category and story line. Adequate sampling was necessary for reasonable assurance of saturation, relevance, workability, and integrality of the chosen core category and establishing the relationships of other categories to this core (Glaser, 1978). Sample size for this study was 11 participants. Theoretical saturation occurred which meant that (a) no new relevant categorical data emerged, (b) category development was dense, and (c) relationships between categories was established and validated (Strauss & Corbin, 1990). Theoretical sampling did not always involve sampling more persons. The researcher also sampled from previously collected data by returning to gathered data such as transcripts or notes to recode in light of additional knowledge gained as the theory emerged.

Data Collection

Data collection and analysis took place simultaneously over a seven-month period. Face-to-face unstructured, audio taped interviews were utilized which were completely transcribed for analysis. Observations made during the interview and any information obtained before or after the tape recorder was turned off were entered as data in field notes. Additional field notes included researcher impressions, feelings, thoughts, and experiences. Transcribed data was identified by code with identity of participants known only to the researcher. Once transcribed, data was transferred to a computer software program called QSR NUD*IST4©, a qualitative data management system on the researcher's personal computer.

Study participants were solicited by methods previously described. Interview sites and times which were convenient for study participants were mutually agreed upon. It was explained to wife caregivers that privacy was essential for the interview and arrangements would need to be made with family members or friends to be with the demented husband while the interview occurred to assure quiet and privacy. Interviews were also scheduled during routine television viewing or nap times of the demented husbands. While many interviews occurred in the participants' homes, other locations, such a quiet room in Adult Day Care Centers or churches were utilized.

Prior to the actual qualitative interview, participants were asked questions from a demographic questionnaire. Information from this questionnaire was utilized for sample description and to verify whether the participant met requirements for eligibility inclusion in the study. Sociodemographic data elicited from the demographic questionnaire included: age, length of time married, number and ages of children, age of the demented husband, length of time the caregiver has been the primary caregiver, length of time the husband has had dementia (when was the diagnosis made), and type of dementia, if known (see Appendix C). Ability of the wife caregiver to appropriately respond to the demographic questionnaire was considered evidence of non cognitive impairment of the wife caregiver. All wife participants were determined to be cognitively eligible to participate in the study.

Interviews lasted approximately 60 to 90 minutes. All study participants were informed at the time of consent that additional interviews might be necessary at dates, times, and sites mutually agreed upon. Even when the spouse was in the home during a

home interview, no behavioral problems or care needs occurred that prevented the participant from comfortably being interviewed.

Additional contextual information was obtained after the qualitative interview through use of specific open-ended questions (see Appendix D) if this information was not offered by the participant during the interview. These questions elicited information regarding educational level of the participant, income adequacy, specific help-seeking instances, and usual social support network. Information obtained from these questions was appended to the qualitative interview and included in data analysis.

Data Coding and Analysis

In grounded theory, coding is the central process by which theories are built from data. Coding “represents the operations by which data are broken down, conceptualized, and put back together in new ways” (Strauss & Corbin, 1990, p. 57). Throughout the coding process two analytic procedures are used; making of comparisons and asking questions. Three types of coding are utilized in grounded theory; open coding, axial coding, and selective coding. These codings are not done sequentially, but simultaneously. The researcher may move among all three types in any coding session, interpreting, asking questions, and making comparisons using the constant comparative method which involves constant comparison of derived concepts, relationships, and hypotheses with data and with previously derived concepts, relationships and hypotheses. This constant comparative method is used jointly with theoretical sampling to generate an integrated and plausible theory with a core category that accounts for most of the variation in a pattern of behavior.

Open coding was the first type of coding utilized. It is “the process of breaking down, comparing, conceptualizing, and categorizing data” (Strauss & Corbin, 1990, p. 61). During this coding, phenomena were named and categorized through close examination of the data. This was accomplished by taking apart observations, sentences, or paragraphs of the first few interviews, generally line-by-line, and giving each individual event or description a name that represented the phenomena. Incidents were compared with like incidents as analysis progressed in order to group and label similar phenomena.

Data were then collapsed and similar concepts were grouped into categories and given a conceptual name that was more abstract than that given to the concepts grouped under it. The name of the category logically related to the data and graphically described it. Some category names came from words or phrases of the informant themselves. These codes are often called “in vivo” codes (Glaser, 1978, p. 70; Strauss, 1987, p. 33). Categories were further developed in terms of their properties which were the characteristics or attributes, and their dimensions, which represented the location of a property along a continuum, or the degree of an attribute.

Throughout the process of open coding, the researcher must think analytically rather than descriptively about the data in order to generate provisional categories and produce generative questions. Basic questions of who, what why, where, when, and how must be asked of the data to “open it up” and “see” with analytic depth and theoretical sensitivity what is there (Strauss & Corbin, 1990). Questions raised in analysis of one interview were used to look for answers in another.

Axial coding utilizes a set of procedures to put data which was taken apart by open coding back together in new ways by making connections between categories and their subcategories. Each category is specified according to: (a) terms that give rise to it, (b) the context in which it is embedded, (c) the action/interaction strategies by which it is handled, managed, and carried out, and (d) consequences of those strategies (Strauss & Corbin, 1990). This results in a paradigm model through which subcategories are linked to a category in a set of relationships. The paradigm model promotes density and precision for each category. As developed through axial coding, the paradigm model appears as:

Causal conditions (antecedents) → Phenomenon → Context →

Intervening Conditions → Action/Interaction Strategies →

Consequences (Strauss & Corbin, 1990, p. 99).

There are four distinct analytic steps which are performed simultaneously during axial coding. These steps are:

1. Hypothetical relating of subcategories to a category by means of statements denoting the nature of the relationship between them and the phenomena.
2. Verification of those hypotheses against the actual data.
3. Continued search for properties of categories and subcategories and the dimensional locations of data (events, happenings, etc...) indicative of them.

4. Beginning exploration of the variation in phenomena by comparing each category and its subcategories for different patterns discovered by comparing dimensional locations of instances of data (Strauss & Corbin, 1990, p. 107).

The purpose of these axial coding procedures is to capture as much of the complexity, movement, and reality of the phenomenon as possible. The discovery of similarities and differences among and within categories is critical to grounded theory.

Selective coding, which is the last type of coding, builds on the basis of axial coding and involves integration at a higher and more abstract level of analysis than axial coding. Most importantly, selective coding involves the identification and selection of a core category which is "... the central phenomenon around which all the other categories are related" (Strauss & Corbin, 1990, p. 116). Selection of the core category involves the explication of a story line which is a conceptualization of the story about the central phenomenon of the study. The core category is identified by examining all the categories and identifying one category that is broad enough to encompass all that has been described in the story. All other categories are then related to the core category by means of the paradigm. The storytelling and its sequential order are the keys to ordering the categories in a clear fashion. Categories are arranged and rearranged in terms of the paradigm until they fit the story and provide an analytic version of the story.

Relationships are validated by means of writing hypothetical statements and returning to the data for verification. Patterns are uncovered and used to group the data accordingly for specificity. Connections are solidified through generating hypotheses,

asking questions, and making comparisons. Categories are filled out, further developed, and refined as necessary. The theory is then laid out narratively and/or diagrammatically as a substantive model. Finally, the theory is validated against the data again to complete the grounding. Any cases not fitting the theory are traced back to determine what conditions caused the variation and these are built into the theory.

The final step in grounded theory analysis involves utilization of a conditional matrix to examine the interaction of the phenomenon within societal contexts. The conditional matrix is used to consider the wide ranges of conditions and consequences related to the phenomenon (Strauss & Corbin, 1990). It enables the researcher to (a) be theoretically sensitive to the range of conditions that might bear on the study phenomenon and the range of potential consequences that result from action/interaction, and (b) systematically relate conditions, actions/interactions, and consequences to a phenomenon, on levels ranging from international to individual. The grounded theory is examined within the context of the conditional matrix by tracing it through conditional paths.

Verification

Three areas are suggested by Strauss and Corbin (1990) as important in judging the trustworthiness of a qualitative study. They suggest that judgements be made regarding: (a) validity, reliability, and credibility of the data, (b) adequacy of the research process, and (c) empirical grounding of the research findings. Strauss and Corbin do not suggest criteria for evaluating validity, reliability, and credibility of data, rather they refer researchers to Miles and Huberman (1994) among others, for these

criteria. Qualitative research evaluation criteria developed by Miles and Huberman (1994), which includes evaluation of data as well as the research process, together with criteria by Strauss and Corbin (1990) for empirical grounding will provide the framework for verification for this study.

Miles and Huberman (1994) propose five criterion for evaluation of qualitative research: (a) objectivity/confirmability, (b) reliability/dependability/auditability, (c) internal validity/credibility/authenticity, (d) external validity/transferability/fittingness, and (e) utilization/application/action/orientation. Each of these areas will be addressed sequentially.

Objectivity/Confirmability

This evaluative criterion of Miles and Huberman (1994) refers to the study's freedom from unacknowledged researcher bias. Essential to this criterion, personal assumptions, values, and biases of the researcher have to be made explicit in the study. For this study, personal biases and values of the researcher regarding the area of study, were made explicit through a bracketing interview which was reviewed by experienced qualitative researchers. Identified assumptions were stated in Chapter One (see pp. 13, 14). Additional measures to insure freedom from researcher bias included cross-checking of participants' stories, critical self-reflection of the researcher's perceptions, review of memos and logs, and use of other qualitative researchers for concurrent data analysis and content verification.

Other areas related to objectivity/confirmability include: (a) explicitness of the study's general methods and procedures with enough detail for others to follow an

“audit trail”, (b) availability of study data for reanalysis, (c) conclusions explicitly linked with exhibits of condensed or displayed data, (d) ability of readers to follow actual sequencing of data collection, processing, condensation, transformation, and display for study conclusions, and (e) consideration of competing hypotheses or rival conclusions (Miles & Huberman, 1994). Chapter Four provides verification for all of these areas through presentation of the analytic and coding process, the narrative story line, and model diagram.

Reliability/Dependability/Auditability

This criterion pertains to consistency and stability of the study over time, and across researchers and methods. It involves aspects of clarity of research questions and congruence with the study design, clear specification of basic paradigms and analytic constructs, adequate agreement of coding checks, and peer or colleague review procedures. If multiple researchers are involved in data collection, comparable data collection protocols would be evaluated as well as agreement and convergence among observers.

Also included in this criterion are questions relating to collection of data across the full range of appropriate settings, times, and respondents, making of quality data checks, and explicitness of status and role of the researcher within the site. This study addressed the criterion through careful adherence to procedures outlined for grounded theory studies by Strauss and Corbin (1990). Since there was only one researcher collecting data, no protocols for multiple field workers is necessary. Examples of how data were coded are included in Chapter Four.

Internal Validity/Credibility/Authenticity

This criterion pertains to the truth and sense value of the study. It includes clarity of linkages, explanation of discrepancies, internal coherence and relation of concepts. Also included are comprehensiveness, richness of the descriptions, and explicitness of rules for confirmation of propositions and hypotheses. This criterion requires that original informants confirm the accuracy of the conclusions. Three of the study participants were asked to review and evaluate the emerging paradigm and substantive theoretical model for 'truthfulness'. Input from other experienced qualitative researchers assisted in assuring the sense value of the study and findings.

Additionally, Miles and Huberman (1994) suggest that it is important to consider how valid and reliable the researcher is as an information gathering instrument. They propose that qualities of a good qualitative researcher-as-instrument include: (a) familiarity with the study phenomena and setting, (b) strong conceptual interests, (c) a multi disciplinary approach as opposed to a single discipline approach, and (d) good investigative skills. This researcher has familiarity with the study phenomena and strong conceptual interests as discussed earlier in this paper. Further, through work conducted as a graduate research assistant and as a member of both the University of Tennessee, Knoxville, College of Nursing Gerontology Research Group and Empathy Research Group, this researcher also had experience with qualitative interviewing, compilation of field notes, and qualitative data analysis.

External Validity/Transferability/Fittingness

This criterion pertains to the larger importance of the study. Issues addressed are limitations of the study, applicability of conclusions and outcomes to other studies, suggestions of settings for further testing of findings, ease of replicability of findings, theoretical diversity permitting broader application, and congruency, connectedness, or confirmation with prior theories. Since this study produced a substantive theory, or one that is generated for specific, circumscribed, and empirical areas of inquiry (Hutchinson, 1993), the theory resulting from this study is applicable only to other closely similar groups. Replication of this research with other caregiver groups would be necessary to determine the applicability of this theory to those groups. Detail provided in description of the study participants allows for comparison with other samples

Utilization/Application/Action/Orientation

This criterion refers to the pragmatic value of the study. Questions applicable in this area include whether potential users will see findings as physically and intellectually accessible, whether there is a catalyzing effect for specific actions as a result of the findings, whether users of the findings experience empowerment or develop and learn new capabilities, and whether problems can actually be solved as a result of the findings. Findings from this study will be published and disseminated. Chapter Five addresses implications and recommendations related to study findings.

Empirical Grounding of the Study

Evaluation criteria developed by Strauss and Corbin (1990) which are specific to empirical grounding of a study include the following:

1. Are concepts generated?
2. Are concepts systematically related?
3. Are there many conceptual linkages and are the categories well developed? Do they have conceptual density?
4. Is much variation built into the theory?
5. Are the broader conditions that affect the phenomenon under study built into its explanation?
6. Has process been taken into account?
7. Do the theoretical findings seem significant and to what extent?

Chapter Four presents a thorough description of the generation of the theory in this study. Additionally, presentation of development of the story line, and embedding of the theory in a conditional matrix also addresses these criteria.

Summary

Grounded theory methodology as outlined by Strauss and Corbin (1990) was used for this study of patterns of help-seeking by older wife caregivers of demented husbands to develop an inductively derived substantive theory that was grounded in the data and reflected the reality of the experience for this group of caregivers. This approach was determined to be most appropriate for the study because it facilitated an understanding of the help-seeking process from the participants' point of view.

Margaret Newman's Theory of Health as Expanding Consciousness (1986, 1994) provided a perspective for interpreting the experiences of wife caregivers and identifying patterns of interaction, thereby providing a framework for development of the emerging theory.

Participant interviews from eleven wife caregivers who met eligibility requirements were transcribed and analyzed using open, axial, and selective coding as described by Strauss and Corbin (1990). Theoretical sampling continued until all categories were well developed and theoretical saturation was reached. The researcher utilized theoretical sensitivity gained as a result of personal and professional experience, familiarity with the literature, and interaction with the data, to provide insight and understanding of patterns and the emerging theory.

Use of grounded theory methodology with a perspective of health as expanding consciousness resulted in identification of a new theory of help-seeking that described the help-seeking process according to a paradigm model. This model included the core category, antecedents, context, intervening conditions, action/interaction strategies, and consequences. The theory was then laid out narratively and figuratively and embedded in a conditional matrix.

Use of a bracketing interview to identify researcher assumptions, cross-checking of participants' stories, critical self-reflection, memoing and log keeping, content verification, and constant comparison of emerging categories with the data assured that all findings were truly grounded in the data and that the study was valid and reliable. Through careful adherence to procedures, reporting of procedural operations,

description of findings with examples of coding and analysis to provide support for how these findings were determined, and discussion of implications and significance, readers should be able to ascertain the verifiability or plausibility of this study. They can then “judge under what conditions the theory might fit with reality, give understanding, and be useful” (Strauss & Corbin, 1990, p. 257) .

CHAPTER FOUR

Findings

This study explored help-seeking by older wife caregivers of demented husbands by using a grounded theory approach. An inductively derived substantive theory called "Help-Seeking Choices: Taking One Day at a Time" emerged from the data analysis. A single dialectic, unifying core category named reaching out/reaching within was identified as being reflective of the phenomenon of central concern in the process of help-seeking by wife caregivers in this study to manage care for their husbands with dementia. This chapter presents the findings of the study including: (a) a description of the study participants, (b) the story line of the theory (c) the paradigm model, (d) the substantive model, (e) the theory, and (f) summary.

Description of Participants

Eleven Caucasian wife caregivers age 60 and older who were caring for their husbands with dementia in the home volunteered to participate in the study. Ages of these women ranged from 63 to 86 years with a mean age of 76.5 years. All wives except one were in their first and only marriages with the current spouse. The one exception was a second marriage that was in the twenty-second year. The other ten marriages ranged in duration from 41 to 62 years with a mean time of 53.4 years. As is common in this cohort of the general population, most husbands were older than the wives. Ages of the husbands ranged from 66 to 87 years with a mean age of 80.8 years.

The majority of the husbands (eight) had a diagnosis of Alzheimer's disease. Two of the husbands had Parkinson's dementia, and one husband had a diagnosis of "hardening of the arteries" given as a cause of his dementia. The length of time since the diagnosis of dementia ranged from three months to eight years with a mean time of 3.9 years, however many wives reported noticing problems for several years prior to diagnosis. Participant characteristics are summarized in Table 4.1

All participants except one, Ellen, had at least one living child. Betty, Jane, Margaret, Anne, Marie, Charlotte, and Helen reported having children who lived close by. Sue had one child who lived about 50 miles away and one living out of state. Laura and Glenda had children who lived considerable distances away. Names and places presented are fictitious to protect participant anonymity

Table 4.1 Participant Characteristics

Characteristic	Mean (years)	Range (years)
Age of wives	76.5	63 - 86
Years married (first marriages)	53.4	41 - 62
Age of husbands	80.8	66 - 87
Diagnosis time	3.9	0.25 - 8

All participants except one were residents of East Tennessee. The one exception resided in a northern state. One participant had recently moved to the area, however the majority had been area residents for many years. Four of the participants resided in metropolitan areas, five in suburban areas, and two in rural areas.

Additionally, the majority of the participants, with two exceptions, considered their income adequate to meet present needs. One wife, Ellen, was still working in a home-based family business. Further demographic data included educational level which ranged from completion of seventh grade to college degrees. Participants actual names were not used to ensure confidentiality. The demographic information emerged from the completion of a demographic questionnaire which was completed prior to the qualitative interview (see Appendix C), information elicited during the qualitative interview, and additional information obtained from questions following the interview to capture contextual information (see Appendix D).

Story Line

The story line is a narrative, analytical description of the main phenomenon of the study and the relationship of the other categories to this phenomenon. This descriptive narrative provides an overview of the essence of the findings of the study. It is a story of the collective experiences of the study participants.

The main story in this study was about wives caring for husbands with dementia who had come to a realization that there was a problem in their lives that might require help. Recognition of the fact that there was something seriously wrong with the spouse, acceptance of direction from others, or recognition of acute or accumulating needs of

the spouse or wife contributed to this realization. Wives responded to this realization by both reaching out to others to involve formal (paid) or informal (unpaid) sources of help, and by reaching within themselves and tapping internal resources to manage aspects of care for the husband and also manage household, financial, and other daily living needs.

The relative proportions of reaching out/reaching within with its properties of managing by self, involving informal help, and involving formal help, varied at any given point in the caregiving experience in terms of intensity, duration, extent, and frequency. Variances occurred along continuums from low to high intensity, short to long duration, light to heavy extent, and sporadic to often frequency. These variations occurred on a fluctuating, continually changing day-to-day basis. Wives made choices to reach out or reach within based upon a multiplicity of internal, relational, situational, and experiential factors which were either hindering or facilitating conditions and also upon the wives perceptions of their own needs and the needs of their spouses.

Reaching out/reaching within evolved and changed through an action/interaction strategy of making choices. Wives' made choices of three dynamic, interconnected, and often overlapping patterns of behaviors. These patterns were avoiding, shouldering, and facing. Avoiding involved ignoring, minimizing, or denying problems as a means of coping. Shouldering involved drawing on internal resources and assuming the burden rather than reaching out. Facing involved acknowledging the need for help and reaching out to obtain it. Evolution through these patterns was not linear, but rather a cyclical process that varied in response to the changing complexities of the caregiving situation

and other life events. However, the pattern of shouldering was always present to some degree. The wives described taking things "one day at a time" when talking about how they managed care and made these pattern choices.

Use of these behavior and relating patterns of avoiding, shouldering, and facing allowed the wives to continue caring for their husbands at home. Depending upon choices made and effectiveness of the help obtained, care was continued with less or greater cost to the wife caregivers. Continuing care with less cost occurred when there were positive consequences from choices made. Reduction in emotional, physical, or financial burden were positive consequences. Continuing care with greater cost occurred when there were negative consequences from choices made. Increased emotional problems, physical or health problems, or financial loss were negative consequences. When choices resulted in greater cost, wives often rethought choices and revised their behavior and relating patterns thereby adjusting the intensity, duration, extent and /or frequency of the proportions of reaching out/reaching within. This resulted in a cyclical pattern where consequences fed into either hindering or facilitating experiential factors affecting future choices, and increased cost of continuing care fed into more need of either spouse or wife providing impetus to make new choices to again reach out/reach within. Reduced cost of continuing care did not necessitate a change in choice of patterns or the relative proportions of reaching out/reaching within utilized by wife caregivers.

The Paradigm Model

In axial coding, subcategories were related to the core category through a paradigm model which was developed as described by Strauss and Corbin (1990). Use of this paradigm model assured that the grounded theory analysis had density and precision. The core category was identified as reaching out/reaching within and all other categories became subcategories.

Open coding, achieved through line-by-line analysis of transcribed interviews, identified concepts or codes. Using the NUD*IST4 © qualitative software program, the concepts were first entered as free nodes and then later grouped into categories which represented concepts according to axial coding schemes. Codes and categories were arranged and rearranged by moving them from node to node and also combined until major categories emerged. After much deliberation, two categories were combined into one major category called reaching out/reaching within, which was identified as the core category and then all the other categories were related to it. Through use of theoretical sampling, data was re-explored to identify properties and dimensions of all categories to assure density and richness of each category. This second level or axial coding is presented in Table 4.2. The paradigm model with the core category of reaching out/reaching within and the related subcategories is outlined in Figure 4.1.

Table 4.2 Second Level Coding

Codes	Categories		Paradigm
	initial	final	Antecedent
first contact crisis	recognition of problem	Realizing: recognition of wrongness	
going public realization	"	"	
early problems	"	"	
diagnosis	"	"	
lost	"	"	
accident	"	"	
medical problem	"	"	
professional direction	direction of others	Realizing: accepting direction of others	Antecedent
Info from friend	"	"	
Info from family	"	"	
Dr. & social worker	"	collapsed into professional direction	
Dr. arranged	"	"	
Dr. says	"	"	
getting away needing help	help needs/caregiver	Realizing: recognizing help needs/caregiver	Antecedent
visit with mother	"	"	
time for housework	"	"	
shopping time	"	"	
mowing	"	"	
repairs/wood	"	"	
appointments	"	"	
get mind off	"	"	
regular help	"	"	
can't do	"	"	
don't need	"	"	
freedom	"	"	
little things	"	"	
rest	"	"	
financial help	"	"	
bookworm	"	"	
time for self	"	"	
health needs	"	"	
fell	"	collapse into health needs	
broke hip	"	"	
lost sight	"	"	

Table 4.2(continued)

Codes	Categories		Paradigm
	initial	final	
can leave	help needs/spouse	Realizing: recognizing	Antecedent
moving	"	help needs/spouse	
emergency	"	"	
up & around	"	"	
complete care	"	"	
till can't handle	"	"	
walking	"	"	
gets bad	"	"	
agitated	"	"	
dead weight	"	"	
doesn't wander	"	"	
food & medicine	"	"	
medical problems	"	"	
grooming/dressing/ toileting	"	"	
children to spend time	"	"	
doing by self	shouldering	Reaching out/	Phenomenon
coping	"	reaching within:	
one day at a time	"	managing by self	
education & experience	"	"	
when combative	managing by self	"	
when looses things	"	"	
when bathing & dressing	"	"	
when upset	"	"	
when has accidents	"	"	
to make for convenience	"	"	
when has seizures	"	"	
to get equipment	"	"	
to move	"	"	
involving family	informal help	Reaching out/	Phenomenon
involving friends	"	reaching within:	
involving neighbors	"	involving informal help	
spiritual help	"	"	
Internet	"	"	
Church	"	"	
pastor	"	collapsed into church	
talking to friends	"	collapsed into involving friends	
grandchildren	"	collapsed into involving family	

Table 4.2(continued)

Codes	Categories		Paradigm
	initial	final	
close neighbors	facilitating factor	facilitating factor: relational	Intervening conditions
family close by	"	"	
give & take	"	"	
good children	"	"	
good friends	"	"	
time	facilitating factor	facilitating factor:	Intervening conditions
financial help	"	situational	
availability	"	"	
can afford	"	"	
doesn't mind	"	"	
family schedules	"	"	
pay	"	"	
gracious	facilitating factor	facilitating factor:	Intervening conditions
spouse happy	"	experiential	
honest	"	"	
sincere	"	"	
dependable	"	"	
understand	"	"	
helpful experiences	"	"	
good care	"	"	
can trust	"	"	
asking is bothering	hindering factor	hindering factor:	Intervening conditions
Independence	"	internal	
Paying for service	"	"	
eligibility impressions	"	"	
didn't know	"	"	
dislike of MD	"	"	
don't need	"	"	
want to pay	"	"	
not freeloader	"	"	
don't want to be burden	"	"	
don't want to make habit	"	"	
not comfortable	"	"	
can't repay	"	"	
ought to do	"	"	
don't understand	"	"	
take care of yourself	"	"	
you do it yourself	"	"	
distrust	"	"	

Table 4.2(continued)

Codes	Categories		Paradigm
	initial	final	
I as we	hindering factor	hindering factor:	Intervening conditions
honoring vows	"	relational	
Protecting	"	"	
not sincere	"	"	
doesn't visit	"	"	
past patterns	"	"	
don't know neighbors	"	"	
lack of friends	"	"	
no children	"	"	
family conflicts	"	"	
don't know	"	"	
time	"	hindering factor:	Intervening conditions
financial problems	"	situational	
spousal reluctance	"	"	
Family conflicts	"	"	
inadequate insurance	"	"	
daughter finances	"	"	
age of friends	"	"	
accessibility	"	"	
satisfied at home	"	"	
not worth it	"	"	
distance	"	"	
driving	"	"	
time & energy	"	"	
not convenient	"	"	
friends limitations	"	"	
friend died	"	"	
not in books	"	"	
not eligible	"	"	
distance	"	"	
not worth it	"	"	
expensive	"	"	
friends busy	"	collapse into busy	
pastor busy	"	"	
worker busy	"	"	
not available	"	"	
tiring	"	"	
refusing help	"	hindering factor:	Intervening conditions
improper medicine	"	experiential	

Table 4.2(continued)

Codes	Categories		Paradigm
	initial	final	
couldn't help	hindering factor	hindering factor:	Intervening conditions
brick wall	"	experiential	
withholding information	"	"	
battle	"	"	
fighting	"	"	
system failing	"	"	
bureaucracy	"	"	
can't reach	"	"	
paper work	"	"	
falling between cracks	"	"	
MD. didn't recognize	"	"	
MD. not understanding	"	"	
weren't available	"	"	
not helpful	"	"	
not honest	"	"	
busy	"	"	
MD. busy	"	"	
waiting	"	"	
no beds	"	"	
not sincere	"	"	
don't come by	"	"	
not sincere	"	"	
bad experiences	"	rename:medical care unhappy	
managing	shouldering	Making choices:	Action/ Interaction Strategy
working around	"	shouldering	
one day at a time	"	"	
maintaining patterns	"	"	
coping	"	"	
take things as they come	"	"	
learn as you go	"	"	
medicating	"	"	
doing	"	"	
adjusting	"	"	
handle myself	"	"	
drawing on experience	"	"	
hiding things	"	"	
counting birds	"	"	
taking keys	"	"	
talking to	"	"	
stretching truth	"	"	

Table 4.2(continued)

Codes	Categories		Paradigm
	initial	final	
locking doors	shouldering	Making choices:	Action/ Interaction Strategy
let him	"	shouldering	
watching	"	"	
take over	"	"	
Doing by self	"	collapse into doing	
seeking information	reaching out	Making choices:	Action/ Interaction Strategy
deciding	"	facing	
planning ahead	"	"	
fighting & continuing	"	"	
using cellular phone	"	"	
settling business	"	"	
talking	"	"	
looking	"	"	
paying	"	"	
attending seminar	"	"	
calling	"	"	
asking for guidance	"	"	
calling & coordinating	"	"	
choosing	"	"	
attending	"	"	
writing	"	"	
donating money	"	"	
told MD	"	"	
contacting	"	"	
belonging	"	"	
seeking placement	"	"	
taking	"	"	
signing on	"	"	
praying	"	"	
Delaying	avoiding	Making choices:	Action/ Interaction Strategy
minimizing	"	avoiding	
maintaining normalcy	"	"	
denying	"	"	
ignoring future	"	"	
hoping	"	"	
forget	"	"	
didn't realize	"	"	
delaying diagnosis	"	"	

Table 4.2(continued)

Codes	Categories		Paradigm
	initial	final	
no plans won't tell	avoiding "	Making choices: avoiding	Action/ Interaction Strategy
get away	reduce burden	Continuing Care:	Consequence
getting self together	"	at less burden/ emotional	
keep me from drowning	"	"	
express feelings	"	"	
different perspective	"	"	
getting by	"	"	
don't know what I'd do	"	"	
happy	"	"	
relief	"	"	
relax	"	"	
refurbish	"	"	
given strength	"	"	
will work out	"	"	
helped me	"	"	
spouse satisfied	"	"	
able to put up	"	"	
get mind off	"	"	
Godsend	"	"	
couldn't get by	"	"	
yell & scream	"	"	
gets easier	"	"	
see how others coping	changes thinking	"	
find out	"	"	
information	"	"	
learned	"	"	
can't get down	"	"	
overcome shyness	"	"	
less wear	"	Continuing care:	Consequence
time	"	at less burden/ physical	
go to Mall	"	"	
relieves me	"	"	
get teeth done	"	"	
fix meals	"	"	
care for house	"	"	
Would be in			

Table 4.2(continued)

Codes	Categories		Paradigm
	initial	final	
nursing home	preventing institutionalization	Continuing Care: at less burden/ physical	Consequence
could not keep	"		
help pay for meds	reduce burden	Continuing care: at less burden/ financial	Consequence
help pay for day care	"		
help meet expenses	"		
disappointed	Problems & disappointment	Continuing care: at greater cost/ emotional	Consequence
won't go back	"		
weren't available	"		
cried	"		
won't do that	"		
spouse didn't like	"		
not same	"		
depressed	"		
get short	"		
no joy	"		
frightened	"		
isolation	"		
not worth it	"	Continuing care : at increased cost/ physical	Consequence
no time/energy	"		
exhausted	"		
health problems	"		
quit work	"	Continuing care: at increased cost/financial	Consequence
financially draining	"		

Antecedents →**Realizing**

recognizing wrongness
 accepting direction from others
 recognizing help needs
 of caregiver
 of spouse

Context →

properties of reaching out/reaching within
 managing by self
 involving informal help
 involving formal help

Dimensions:

Intensity: high <-----> low
 Duration: long <-----> short
 Extent: heavy <-----> light
 Frequency: often <-----> sporadic

Phenomenon →**Reaching out/reaching within****Intervening Conditions →****Facilitating and hindering factors**

internal
 relational
 situational
 experiential

Action/Interaction Strategies →**Making choices**

avoiding
 shouldering
 facing

Consequences**Continuing Care**

at less cost at greater cost
 emotional
 physical
 financial

Figure 4.1 Paradigm Model

Conceptual Definitions

Conceptual definitions were developed for each of the major categories and subcategories of the theory. It was determined that saturation had occurred in all the categories and subcategories. The conceptual definitions are as follows:

Realizing---Antecedent. A conscious awareness of the presence of a problem that will require some action.

Recognizing wrongness---Antecedent property. Events that made caregiver realize that spouse had a real problem.

Accepting direction from others---Antecedent property. Accepting advice or information from others or allowing them to arrange contact help for wives.

Recognizing help needs---Antecedent property. Actual or perceived needs identified by wife. May be wife needs (caregiver needs) or husband needs (spouse needs).

Reaching out/reaching within---Core category. A dialectic fusion of reaching within oneself and reaching outside of self to external sources for help. Properties of reaching out/reaching within along with dimensions form the Context.

Managing by self --- Context. Reaching within self to tap into internal resources to manage.

Involving informal help--- Context. Reaching out to all help that is not paid.

Involving formal help--- Context. Reaching out to all help paid by caregivers, third party payers, donations, or taxpayers.

Facilitating factors---Intervening conditions. Factors that help caregivers make choices to reach out/reach within or increase likelihood that they will use a particular strategy or source.

Hindering factors---Intervening conditions. Factors that act as barriers to making choices of reaching out /reaching within or decrease the likelihood that a caregiver will use a particular strategy.

Internal---Subcategory of facilitating or hindering factors: Factors actual or perceived within the wife that affect reaching out/reaching within choices. Includes attitudes & knowledge.

Relational---Subcategory of facilitating or hindering factors: Factors arising from relationships of the wife with spouse, family or others or relationships between family & spouse that affect reaching out/reaching within choices.

Situational---Subcategory of facilitating or hindering factors: Factors arising outside of wife and husband, within systems or others, that affect reaching out/reaching within choices.

Experiential---Subcategory of facilitating or hindering factors: Previous experiences of wife or spouse that affect further reaching out/reaching within choices.

Making Choices--- Action/Interaction strategy. Decisions made by the wife to choose particular behavior/relating patterns to reach out or reach within.

Avoiding--- Behavior/relating pattern associated with making choices. Pattern in which wife ignores or minimizes the problem as a way of coping and dealing with it.

Shouldering--- Behavior/relating pattern associated with making choices. Pattern in which the wife relies on internal resources and assumes caregiving burden rather than reaching out.

Facing--- Behavior/relating pattern associated with making choices. Pattern in which the wife acknowledges the need to reach out & does.

Continuing Care---Consequence. Being able to continue to care for the husband at home as a result of reaching out/reaching within choices.

Less cost- --Property of Consequence. Lessening of physical, emotional, or financial burden of caregiving as a result of reaching out/reaching within choices.

Greater cost---Property of Consequence. Increased physical, emotional, or financial burden of caregiving as a result of reaching out/reaching within choices.

Emotional---Subcategory of Continuing Care/ Less cost or Greater cost.
Psychological stresses of caregiving

Physical--- Subcategory of Continuing Care/ Less cost or Greater cost. Physical effects of caregiving

Financial--Subcategory of Continuing Care/ Less cost or Greater cost. Actual monetary costs.

Antecedent: Realizing

Reaching out/reaching within was precipitated in this study by realization. Prior to doing anything to manage the situation, the wives had to first come to a conscious awareness of a problem with their husbands that required some attention. This

realization came about in three possible ways; recognizing wrongness, accepting direction from others, or recognizing help needs.

Recognizing Wrongness. Many women described vague feelings that something may not have been right, but it was not until they recognized that a real problem existed that any reaching out/reaching within occurred. At times this recognition was dramatic as when a crisis occurred that was so outstanding that there was no longer any doubt that a major problem existed. Instances of the husbands becoming lost was a common example of this type of event. Jane described how her husband became lost for nearly a day:

Two o'clock rolled around and I thought, well, he's been gone an awfully long time, and I guess he's just loading up. I still didn't think anything about it. Three o'clock, four o'clock, and I thought, well, something is wrong, so I better start trying to call around. So I called my next door neighbor in Avon. and she said "Well, Tom was here earlier." Said "He's been gone a long time." And I said "If he doesn't get home before dark, he'll never find his way back here".... So, finally about six o'clock the next morning, Thanksgiving morning, 911 called me and said, "Mrs. W. we've got your husband, and he's OK." Said "They found him, or they picked him up for driving erratically in Oslo." And they said "They are taking him to the police department now."

Margaret also related an instance of her husband becoming lost:

I thought maybe I ought to call and see if he had got there alright. So I did and he had not got there in due time. So I thought, well, I better get in the car and see if I can find him. So I went down, checked Cox. Road, couldn't find him. So then I went down Albi Road. He, and he had gotten lost. He went down Albi. Road instead of Cox. Road. And he was beside himself! He didn't.. he didn't know which way to go. So I realized then that, well, I was right.

Catastrophic changes in the relationship between the couple as a result of the husbands' behaviors was another factor that precipitated recognition of wrongness. One such situation was related by Charlotte:

I just got me a bite to eat. Went to the den. I was sitting there and he came and he said "Are you sleeping?" And I said, I started to say "No." and he said "Well, this will wake you up. In the morning I'm calling a lawyer, I want a divorce!"

Car accidents were also catalysts to recognition of wrongness in a number of cases related by the wives. Charlotte described her husband's problem.

Oh, he had several (accidents). And that's one of the reasons we were having trouble with insurance. Because he had accident after accident. And they said "I'm not insuring you anymore."

In other cases, recognition of wrongness was more an accumulation of instances of behavior or relational problems that the husband was having. The cumulative effect of these problems finally brought about a recognition that something was not right.

Anne described some early problems with her husband.

Well, he would get, he would get really angry about things that he was imagining that were not in truth any. But he would just get furious, you know, thinking. And ah, that's one of the most of the things that I noticed to begin with that was not like himself, you know.

Accepting direction from others . Direction of others also led to a realization that a problem existed or a realization that help was needed. This direction came from medical professionals, friends, and family members. Eventually these wives sought diagnoses for their husbands. When a diagnosis was made, the problem was out in the open and recognized. Jane recounted the following interaction with her family physician:

So one day we went down there for his checkup. And he said "Well, how's his Alzheimer's doing?" And I thought, well, I guess maybe he does have Alzheimer's if his medical doctor has said this.

Ellen described early problems with her husband which finally resulted in specific direction from a physician:

Oh, he was hearing bugs! And then I had to call Jim or George. This was one, two, three, in the morning sometimes. We had to take him to the hospital. And they run, they had a doctor in to check his ears. And Dr. Moore says "It costs you money when you go to the hospital like that. Albert didn't say nothing. He didn't care. So finally, they were getting so used to him in that hospital, just checking his ears. There's nothing in his ears. They flushed his ears and everything sometimes. So this one doctor, I've got the paper on it...And he says to Albert, "You've got to see a psychiatrist. There's something wrong with you." Which there was. And he did see a psychiatrist at the VA.

Family members often gave direction to the wives in the form of suggestions or information about treatment or diagnosis. Glenda related her experience in finding treatment for her husband:

He has a cousin that's an administrator at the University Hospital in Jonesville. And she called within the last six months, I guess. And told us that they had such a good Parkinson's clinic there and were doing so many new things and helping people that she wished that we'd come down there. And she could get us in with the doctors that we needed to see. So we did that. And that's what we've done.

Direction of others could come from a number of sources. Charlotte recalled receiving direction from her pastor during the crisis when her husband was talking about a divorce:

Well, what our priest did, he gave me numbers to call and we went to this group called PAG... And I talked to him and he gave me these numbers to call, telephone numbers to call. So, that's the way that got started. Cause I didn't ever dream it was something like that, I really didn't!

Recognizing help needs. A major factor contributing to a realization that help was needed or a problem really existed was accumulating help needs of either spouse or wife or both. As need levels increased, it eventually became apparent to the wives that some sort of action was required. Needs of husbands as related by the wives were primarily physical or behavioral needs. Some of the husbands could be left alone for

short periods of time while others could not. Some husbands were mobile, others immobile. Some had multiple medical problems in addition to the dementia. Immobility of husbands had positive and negative impacts on needs as Anne related when discussing her husband:

Yes, I do leave him alone because he can't get out of bed. And I have to buy groceries. I have to buy medicine...But, well, just someone to help me get him out of bed. And, and that, that's the main thing.... Sometimes, a few times, he's slid out of his wheelchair and we'll have to get the lift to put him back in it.

Descriptions of husbands' grooming, bathing, dressing, toileting, feeding, and ambulating needs were also related by wives. Ellen described how her husband's problems walking were creating a need for action:

Oh yeah, I think I can still take care of Albert yet. But I don't think he's that bad yet. But ah, the main thing, his walking. Its getting worse and worse. And when his walking is getting worse, then I have to do something.

Marie described how a change in her husband's condition affected his toileting needs:

He had a sick spell just recently that ah, he wasn't responsive like he is. But in fact, ah, toilet habits were so bad then I had to clean up. And I still do yet. And he said, he calls me Sissy, he says "Sissy, I try awfully hard."

Another need of spouses that was discussed by the wives was the need to be watched for wandering. Betty told of her husband's wandering problem:

And he wanders. He goes, we live on a farm. He goes for a walk and then I spend an hour hunting cause he doesn't come home when I call. We have a dog that goes with him and the dog comes (laughs). So I know which way to go.

Further types of needs included need for intervention in behavioral problems and need for care for medical problems. Helen described night time needs of her husband who suffers from serious sleep apnea and has to be on BIPAP at night:

And ah, also he detaches. He was really good about it, detaching his mask from the tube and then reattaching it when he went back to bed. And ah, turning off the machine, turning it back on. But now, as you can understand, well, there are, at times, when he will get back in bed, not reattach it, but turn the machine back on. But be lying there with the mask. Of course he can get air, but not what he needs to stay alive! He's got to have that. Because at the time that his ah, first tests were made, they, he was, he stopped breathing 142 times or more.

Wives told of numerous emotional, physical, financial, and social, needs for themselves and also of needs for assistance in the management of the home and finances. These household and financial tasks were often previously handled by the husbands, but now had been assumed by the wives as the husbands' conditions deteriorated, further adding to the burden placed upon the wife caregivers. One of the major needs of wives was a need for time; time to get away, time to shop, time for appointments, time to do housework, and time for self to do enjoyable activities. Margaret related need for time to get away.

Ah, but if, and, and somebody, if they could just stay with him and let me get out a little bit. Because I find that the more you stay at home, the more convenient it seems to be, just to stay with it. And I don't think that's good all the time. I think you do need a little break.

Betty discussed her need to do some housekeeping.

You know your housework gets a little behind. I don't pile my Tupperware or anything. I don't stack it, that sort of thing. I just need some time at home every so often to catch up with cleaning closets and that. Cause I spend a lot of time just sitting with him.

Sue discussed her need to be able to take time for doctor or dental appointments:

The only time is when I need a doctor's appointment or a dental appointment. I take him to Waterford and that has just started within the last year probably. But I still have not had my doctor's appointment.

Health problems of caregivers also contributed to need of caregivers for assistance with the care of the husband or the household. Several of the wives were experiencing major health problems of their own which provided an impetus for seeking help. Marie was experiencing vision problems and had just undergone surgery to attempt to correct her eyesight.

But this has just been a month now. I don't know what we'll do. What our ah, what will happen if I do go blind. See, there's several options there and one of them is I might go blind. But they wanted to try something because ah, they're afraid this eye is going to do it like this one did.

Helen described health problems that she was having that were forcing her to seek help for her husband and housework.

Totally, I'm not, I'm ah, I've had a host of TIAs. And ah, and I'm on Plavix and Aspirin both. And that's why I bruise....And I can tell sometimes that I'm.. the last day or two, I've been shocked to discover that I'm ah, actually not thinking correctly. And little some things, and its a shock! Because I have to think correctly.

Wives caring for husbands with dementia often did not get enough rest, especially when the husbands were restless at night. Helen expressed great concern about her health and the need for rest:

And ah, I keep wondering. I do, I do very well physically when I get a lot of rest. But I almost never get a lot of rest. And ah, I keep wondering how am I gonna manage the nights. Because that's where, that's where the only chance I have to recoup.

Other help needs of wives were for yard work, home maintenance, and help with financial matters like book work. Charlotte described her need.

I used to do all the mowing. I like to. And I wanted to do, its good exercise. And I liked to even when I used the hand mower that pulled along. Then used the riding mower. And I liked it cause I did it to suit me. I run up things nice and

neat. And then I knew I couldn't do it anymore. And when I said I was going to get somebody, he was horrified.

Realization of the presence of a problem was an antecedent to the phenomenon of reaching out/reaching within for the wife caregivers in this study. This realization came about as a recognition of wrongness, acceptance of direction from others, or because recognition of mounting help needs. Once realization occurred, the main phenomenon of reaching out/reaching within unfolded.

Phenomenon: Reaching out/Reaching within

The core category or phenomenon identified in this study was reaching out/reaching within. The wife caregivers in this study described reaching out/reaching within as how they managed care for their husbands with dementia. The lives of these women were consumed by the day to day struggle to adjust reaching out/reaching within to provide adequate care for their husbands, manage the household, and perform the myriad of other activities that were required to continue to keep the husbands at home. The properties of reaching out/reaching within were identified as managing by self, involving informal help and involving formal help. The dimensions of these properties were discovered to be intensity, duration, extent, and frequency.

Managing by self. Managing by self was reflective of the reaching within aspect of the core category. It was defined as reaching within self to tap internal resources to manage. This aspect was always present as the wives managed care for their husbands and daily activities, no matter what type or extent of reaching out was used. Numerous stories were recounted of instances of managing by self in day-to-day life.

Wives gave numerous examples of managing by self for a variety of day-to-day problems that they encountered with their husbands. They described managing when husbands lost things, when they were combative, when they were upset, when there were problems with bathing and dressing, when the husband was incontinent, when there were seizures, and when husbands had to be moved. Some of these examples can be found in the section on Action/Interaction Strategies since the wives described specific strategies they used to manage these situations. One example was given by Anne who related the following of how she managed when her husband slid out of his wheelchair:

Well, I, I call the office of the home health people. But, but the last time he did that, I did it by myself. I watched them when they, you know, how they did it. And I managed to get him back up. But ah, it, its not easy!

Charlotte also remembered an incident when she had to manage moving her husband by herself:

And I came home one day and he had this big sprayer, five gallon sprayer on his back. And he was just standing out in the garden. He's always loved to garden. So I went up to him and I said "You having a problem?" He said "Yeah, help me get it off." So I got it off and he took a step or two and he said "I can't walk. You help me walk." So I took two steps and he said "I can't do it. You get the little wagon." Well, we have a little children's wagon. I, you know, thought I don't believe I can pull him in that wagon, especially on that grass. I took him and he got in the wagon and I pulled it! (laughs). I pulled it and got it back up to the house and pulled him up to a chair.

Managing a husband who was upset or combative was a problem for several of the wives. Betty related an instance where she had to handle such a problem:

Yeah, he got upset that night pretty bad. I just closed the door and fastened it. He can't figure out how to unlock the door. So I went ahead and locked the bathroom and the bedroom, Course he was alright the next day. He didn't,

wasn't bothered at all. So that's the things that happen and you just take them one day at a time.

Managing by self often involved modifying of the physical environment for the spouse and caregiver. Some of the wives changed the physical layout of their homes in order to better manage the care of their husbands. Betty described the changes she made in response to problems her husband was having:

There's nobody here but just us. Well, we moved downstairs. There's too many door upstairs. That's another project we had to do. There's four big bedrooms and the closets and hallways and he just, the doors would be so confusing to him. he'd just open the closet door to use the bathroom, that sort of thing. So we closed the upstairs and came down stairs. It's really more convenient, that sort of thing.

Wives varied, on a day-to-day basis, the relative proportions of managing by self to the proportions of involving informal and formal help. However, managing by self was always present to some degree. Most frequently this was to a high degree no matter what other sources of help were utilized.

Involving informal help. The reaching out component of the phenomenon of central concern in this study encompassed involvement by the wife caregivers of both informal and formal sources of help. Informal sources were defined as those sources that were not paid and included family, friends, neighbors, and church members.

Families were the most frequent source of help for all the wife caregivers. This family help came from children, grandchildren, brothers, sisters, nieces, nephews, or in-laws.

Mary told of help that she received from her granddaughter:

Our granddaughter, our one and only granddaughter, we have eight grandsons, one granddaughter, and one great granddaughter. And the granddaughter has formed a pattern of having big daddy for supper every Thursday evening, almost every Thursday evening. And ah, and that has been great! I would take him to

their house and then go home and work on the church history and whatever. Or she would. And then, and then, her husband and the baby would bring him home, or she would. And that's out of the kindness of her heart.

Jane related how when she was having problems paying for day care for her husband, her husband's brother and daughter helped her out financially:

Then his brother in Baltimore says "Hey, he needs more. So I will pay for another day for him to go." So with his financial help and his daughter in Florida helping out, that makes it possible for us to send him three days a week.

Anne was receiving extensive help from her daughter and other family members.

She described some of the things they helped her with:

Well, Carol helps me with my book work. All the bills and everything that takes brains (laughs). And all the bills that come in and all that....She's ah, papered my kitchen, and ah, oh, she runs errands for me if I can't go. And ah, she brings in goodies a lot of times that she's baked at home and brought in. And yeah, she helps get me the doctor appointments worked out and everything.... A few times I've had help when I really needed or wanted to go somewhere. My sister's helped. And ah, my son when he, when he can get free.

Laura's family lived a considerable distance away, so she relied more on assistance from friends. She described getting help from a friend when she went on a vacation with her husband.

Well, flying out, I don't know whether it was the altitude or what. Ah, luckily I had a lawyer friend with me cause he was going to go skiing too. And ah, he ah, he got so he, he didn't want to walk. And he just acted so funny, so we got a wheelchair to wheel him in cause we had to stop over in Chicago and it wasn't a direct flight.

Many of the women had neighbors that they relied on in varying degrees to help with either managing care for the husband, home maintenance needs, or emergencies.

Margaret described times when her neighbors helped:

Now I have, we have a couple that live in the house next to us. They have just this summer started their own little business...But now, they've been very good

to, if ah, he has wandered across the tennis court or something like that. And of course, they were very quick to go and find him and get him back.

Technology provided a source of informal help for some of the wives. Use of the Internet or cellular phones assisted these wives in managing care or handling the frustrations they experienced in providing such care. Security systems provided safety. Jane found an informal caregivers' support group on the Internet. She described getting help from that source:

I'm in with the, um, the caregivers' group on the Internet and that gives me some help. And I can go in there and if I'm having a bad day, I can yell and I can scream, and I can put all those marks.

Mary, kept in touch with the volunteer she had staying with her husband by using a cellular phone when she had to run errands:

And I always have the phone (takes cell phone out of purse) with me. And ah, Jerry knows how to reach me on the cellular phone. He has the number. And Jerry is not afraid. He's not afraid to call.

Helen related how a home security system assisted her on a daily basis:

I did have an ADT System put in. And I'm glad I did because if something were to happen, and he were to go out of the house, I would be awakened... I'll know it. I'll know it. And ah, and when he leaves the house, I can, when he goes out during the day, I can see which door he's gone out by.

Nearly all the wives described the importance of their spiritual beliefs as an source of help in managing to get by day by day. They would reach out to a higher being than themselves to assist in coping with the problems, fears, and disappointments that they were facing in the caregiving experience. Only one wife did not discuss spirituality as an important informal resource. Mary described how she sought help from a higher source:

I have, I could never remember a time in my life when I had not had total faith in God. And ah, it never once has occurred to me that any of the undesirable things that have happened to me or my family or anybody are, are God's fault. I mean, that kind of thing never passes through my head. I don't know how people can think that. And I do, ah, I think increasingly now, I am increasingly aware of, how wonderful it is that I ah, do have faith. It's not as deep as it should be. And its not as close as it should be. But ah, its ah, yes, a powerful, powerful aspect.

Glenda related how she received help from her beliefs:

So I don't know what we'll do. Just wait and see. let the Lord take care of us...And he has, so far. We've been very, very lucky. And ah, blessed in a lot of ways that we don't deserve. Just thank him and keep going (tears in eyes).

All the wives were reaching out to informal sources of help. Family help was the first and most frequent source followed by friends and neighbors especially if family was not geographically close to the caregiver. Another frequent and important source of informal help to these women was their spiritual beliefs. These sources were used frequently and in conjunction with managing by self and reaching out to formal sources of help to manage day to day care of the husband and the household.

Involving formal help. Formal help complimented and augmented informal help and managing by self for the wife caregivers. Formal help was defined as all help that was paid for either by the caregiver, third party payers, donations, or taxpayer monies. All of the wife caregivers had sought and utilized formal help at some point in the caregiving experience. For some it was merely reaching out to a physician for diagnosis of the problem or taking the spouse to a hospital or clinic for a health-related problem. Other wives had sought help from an extensive array of formal sources.

The variety of formal help used by these women was impressive. Twenty-five individual sources of formal help were used by these women to either manage direct

care of the husband, household care or associated activities such as legal or financial matters. Services often used on a regular basis included home health, day care, therapists, contract services such as sitters, personal care assistants, lawn and cleaning help, and maintenance help. Anne described the help that she received from home health:

Well, they bathe him. Now that's what the aides do. And when the nurses come, they, they draw blood for.. to check, see he's on Coumadin and they draw blood to check that. See if its that's right, you know, whether its too thick or too thin or whatever. The nurses do that. And the nurses, he has a catheter, and they change that. And ah, I guess that's the main thing that the real nurses do. Well, they dress his wounds, you know, wherever they are... Ah, the aides come every day. And, and ah, the nurses, unless its something unexpected turns up, why they come like three times a week.

Glenda described all the help she received from a person she hired through a non-profit personal and home care assistance program for elders.

Oh, she's a jewel. She does everything. She'll do anything. She cooks, ah for him, She takes him up and gives him his shower. And then brings him back down. He likes peanuts and Coca Cola (laughs). She fixes that. Dresses him and then he takes a nap, usually in the morning... And ah, they are supposed to help you in the house if you need it. Like Millie will ah, run the vacuum downstairs and ah, clean the, she cleans the bathroom upstairs after she showers him. And ah, she keeps this part of the house livable for us, you know. She, she's real good. She does the laundry and all.

Laura had originally hired a girl only to help with cleaning, but found that the cleaning girl could help her with the care of her husband as well:

I have this girl I've had for years comes in and cleans twice a week. And he adores her. And he got so, he wouldn't let me give him a bath. So she tried it, and he loved it! So then I had her twice a week, give him a bath. The rest of the time, he doesn't want a bath.

An unexpected finding of this study was that four of the wives used 911 as a source of help several times or more and had come to depend on 911 as a resource in the

frequent emergency situations which they experienced with their spouses. Glenda

described two times when she used 911 in a three or four month time period:

I was taking him to the doctor and he was upstairs and he fell off the bed. And I could not get him up by myself. And that was the first time, somebody told me to call the fire department. And they are right down the street from us... I called 911 and asked, told them what the problem was. And the truck was here in less than five minutes. And they come in, come, said "That's what we're here for." And ah, one day Harry, ah, after this was not too long ago, I parked him in the car at the market to go in and pick up something real quick. And when I came out, he had locked the car. And I had, the key was in the car. I didn't have an extra key. And I couldn't, couldn't get him to know how to unlock the door! (laughs) And he had cut the engine off so he didn't have air conditioning. And it was back when it was real warm. And um, someone went and called the fire department, and they came over in that big fire truck!

And finally, she related a third experience:

But he got out of the car and he fell on the concrete floor out there and cut his eye real bad. Up on the head here (points to above eyebrow). And of course, you, know, you bleed so profusely and everything. So, I came, I came in to, it was the third of July and all the neighbors, we don't have too many men here, but they were all gone out of town. I knew it. So I came in and called 911 and ah, asked for an ambulance to be sent out immediately!

In the same vein, Ellen relied on the police as a regular source of help when her husband would wander off. She related one particular experience:

Oh, then Sunday, that one Sunday, he went across the highway. He wanted to go to that motel. And Jimmy hollered at me. He says "Ellen, Albert went across the highway!" I says "He did?" So I says "OK. I'm gonna call the cops." And so the cops came and I ran out there, and Albert was just gonna go across the highway. You should have seen the cars that hadda stop.

Jane found the drug company that produces Aracept to be a source of help when her insurance company refused to pay for the medication. She related:

Well then, Emily told me about Pfizer Company and ah, patient help line. So I called them. "Well, he will be denied to start with because you all have insurance that covers drugs." I said "But it doesn't cover this." "Well, you still have insurance that covers drugs. He will be denied, but you can appeal it." And

ah, so he said to call them back in about three or four months. In the meantime, they would send papers to the doctor's office for him to fill out.

Only one caregiver utilized transportation services as a source of help. Anne described using this service:

So see, we have this transportation here. I don't know if its a state or county thing, but they have ah, vans that have lifts on them. And course, that's the only way we can get him to the hospital, is in his wheelchair or to the doctor. So they come. You have to call them, you know, and make your date.

Finally, wives reached out to professionals for help with bookkeeping, legal and financial matters such tax bills, managing investments, and drawing up durable power of attorney and living will forms. Glenda described how she relied on her CPA:

And we are lucky to have a good CPA man. He worked with Harry. He's a CPA and he did the bank work. So, you know, we're good friends with him. And he's real good about making sure that your ah, tax work is always done and ah, he'll call. Well, he comes by a lot of times and just to see what we need. And ah, he always makes sure that I get the estimated tax form in on time and all.

At any given point in time, wives were both reaching out/reaching within in varying proportions. At all times, managing by self was present. Informal and formal help was not always present, but informal help was frequently used, especially family help and spiritual help. A large variety of formal help was used, but not all wives used formal help after getting an initial diagnosis. Several wives utilized formal help only for emergency care or when a medical condition warranted professional help. These situations formed the context of the paradigm.

Context

The context of the paradigm model represents the specific set of properties that pertain to the phenomenon and more, specifically the location of events or incidents

pertaining to a phenomenon along a dimensional range (Strauss & Corbin, 1990). The properties associated with reaching out/reaching within were managing by self, involving informal help, and involving formal help. These properties occurred along dimensional ranges of intensity, duration, extent, and frequency. Context is also “the particular set of conditions within which the action/interaction strategies are taken to manage, handle, carry out, and respond to a specific phenomenon (Strauss & Corbin, 1990, p. 101). These conditions or properties provided a context for the action/interaction strategy of making choices. A more detailed description of these relationships follows in the next sections. However, as examples, under conditions of managing by self, wife caregivers make choices to carry out strategies of avoiding or shouldering and under conditions of informal or formal help, wife caregivers make choices to carry out the strategy of facing. Intervening conditions also affected these choices, contributed to context, and are the next part of the paradigm model.

Intervening Conditions

Intervening conditions comprise the broader structural context pertaining to a phenomenon (Strauss & Corbin, 1990). They act as either facilitating or hindering (constraining) factors for the action/interaction strategy of the paradigm model. In this study, facilitating and hindering intervening factors were grouped as internal, relational, situation, and experiential factors. These factors affected reaching out/reaching within choices by the wives. Internal factors were those factors, actual or perceived within the wife. Relational factors were factors arising from relationships of the wife with spouse, family, or others or relationships between family and spouse. Situational factors arose

outside of either husband or wife and were within systems or others. Experiential factors were previous experiences of wives or spouses.

Facilitating conditions/ Managing by self. These conditions helped caregivers make choices to reach within or increased the likelihood that they would use a particular strategy or source associated with managing by self. Help needs of the spouse in addition to acting as antecedents to reaching out/reaching within, were also situational facilitating factors to wives making choices to manage by self when the spousal needs were minimal or could be easily managed by the wives. Margaret described how she could leave her husband alone to do the things that she needed to do, thereby facilitating her decision to manage by self in this instance:

He does stay here for me to get out and go to the grocery store. He ah, he doesn't walk very well anymore. I'm not afraid of his wandering off. And ah, he putters around here in the house. Ah, of course, ah, if I'm going to be gone at a meal, I can leave him some food and if he thinks of it, he'll eat it. But I figure, well, if he gets hungry enough, he's gonna, he'll find it.

Education and experience of participants provided internal facilitating factors to managing by self as discussed and illustrated earlier in this paper. Wives frequently described past experiences that provided them with the knowledge or disposition to provide care for their husbands. These experiences could be educational as in the case of Betty who was a former nurse and had worked in geriatrics explained:

I don't think I could put up with this if I didn't understand it this well. I think Oliver would be in a nursing home if I didn't know...Yes, I think working twelve, almost thirteen years in the nursing home gives you an idea of what is there and also what's coming.

Another life experience that the wives used to draw on to manage by self was previous family caregiving experiences. For Marie, early life experiences shaped

her attitude about managing problems by herself. The patterns that she formed during these early years were patterns that she used in managing care for her husband. She related:

Maybe you need to know too, I ah, practically raised my brothers and sisters. My father died when we were young. Mother had five children and I was the oldest. And um, so I ah, ..She always put me in charge.... I ah, was sick a long time when I was younger. I ah, had a period there where I would ah, go to the hospital for, stay three months. In fact I started school, my schooling in the hospital... And ah, then I'd come home maybe a month or six weeks. Did that for about four years. And then ah, after that, I ah, had a, walked on crutches. Had a cast on from my toes to my waist and walked with crutches. Course that was confining, you know. Ah, and then graduated to a brace. So I had seven years that I believe from the time I was four years old until I was eleven. And ah, so I've been having to take care of, you know, adjust, a good part of my life to different situations...I just, ah, I just adjust, that's all. I can say I haven't thought of it though until I'm talking to you (laughs). But possibly that's the reason. Because I don't know, I don't think it, I don't think my children could adjust like that.

Jane described how her husband prepared her to manage on her own:

I've always been a very shy person. And um, but, for about the past four, five years, Tom helped me a lot to overcome my shyness. This is when he was at himself. Um, he taught me more how to take care of myself. I said "But I don't want to do this." He says "You're gonna learn to do it because I won't always be around to help you." And ah, its a good thing.

Hindering conditions/Managing by self. Hindering conditions to managing by self included help needs of the spouse that the wife could not handle, health problems of the wife, and home maintenance needs of the wife that could not be handled by self. Illustrations of caregiver health problems were given earlier. Charlotte described a home maintenance need that she could not manage by herself:

I think we're gonna have drainage problems because back in the, at some point in the summer when you have these hard rains, we had water coming in the window well and bringing mud and water into the basement.

Facilitating conditions/Informal and formal help. Making choices to reach out to informal or formal sources of help was facilitated by a number of conditions. Internal facilitating factors included being comfortable with computers, having no pride about asking for help, and satisfaction with services. Experiential facilitating factors included positive experiences that the wives had when they asked family, friends, or neighbors for assistance or when they utilized services. Relational facilitating factors for making choices to reach out to informal help included family support, good friends, good children, close family, close friends, and patterns of give and take between the caregivers and others. Spousal acceptance of services positively affected choices by wives to utilize formal services. Laura described how her husband's acceptance of supervision by staff when she attended an Alzheimer's support group meeting impacted her decision to try day care:

First time I ever left him was when we went to that meeting where you were, That nice man took him and he went right off with him! And had a good time and came back and was perfectly happy. Now whether that will happen here or not, I don't know. I've never tried it here.

Helen described how the relationship between her husband and the children affected her decisions to ask them for help:

I feel perfectly safe ah, the boys, both our sons are extremely good with him and being with their father. And ah, wherever they are, very, very, ah, very, I just can't say enough about the way that they treat him. And then we have one daughter who lives in Charleston that, I would certainly trust him with her... And ah, all other things being equal, she will come at the drop of a hat, and ah take vacation time, you know, and ah, to come and be with us.

Situational facilitating factors for making choices to reach out to informal or formal sources included availability, time, affordability, family schedules, honesty of

workers, and the fact that the husband didn't mind being with certain people. Betty discussed how the schedules of her children made them available to help at almost any time:

I'd call my son. He works nights ICU at the hospital, so he's at home sleeping in the day and evening. And my daughter is next. She lives about a half hour from here. She works the evening shift... They're close and their time is staggered, so that they could come when I need them.

Hindering conditions/Informal and formal help. Hindering factors to making choices to reach out to informal or formal sources were multitudinous. In fact, it was very obvious throughout the study that hindering factors were much more plentiful than facilitating factors for making choices to reach out. Many of the internal hindering factors revolved around wives' desires to be independent from outside help. Laura strongly expressed this feeling:

Just do it and forget trying to go make other people try to go help you. Take care of yourself, you know. Do it yourself. Course, I've been in business all my life, you know. So, maybe that's why I don't think, you handle problems in business and unions. I had unions, I had union problems. You handle these yourself. You don't go crying to somebody or expecting your son to come in and help you or your brother to come in and help you. Um, you do it yourself! And you shut your mouth and do it!

Sue expressed the desire by wife caregivers not to be indebted to others when she talked about her feelings of getting help from people who wouldn't accept pay:

Now if those people would let me pay them, and they wanted it for a job, yes, yes. But if they're gonna come in here and not take any pay, no! ... Why I couldn't repay them. And I who knows, I may be so completely washed out after this is over. You know, generally you can't repay the people that have helped you... Well, I'm not a freeloader! No, I'm not a freeloader!

Many wives felt that asking others for help was bothering them and they didn't want to be a burden on others. Ellen gave her views on asking for help when he husband became agitated in the evening:

Sometimes he'll be sleeping a lot. A lot of times he'll sleep. All of a sudden he'll wake up and he'll say "Oh this horse is running in my yard. Oh, there's a young girl that got killed on the highway. See, he gets real bad. And that's kind of late in the evening. And then I don't know, I hate to bother people just to come in a few little minutes when he gets like that. He goes in streaks.

Another major internal hindering factor to using formal services was a lack of knowledge regarding available services or mistaken impressions that the caregiver or spouse was not eligible for services. Eight of the wives had never seen a service directory for their county of residence, nor were they aware that one existed until informed by the nurse researcher. This was surprising, since many of the husbands had been evaluated by geriatric assessment teams who should have been providing information and referrals. Further, agencies contacted by the wives did not seem to be aware of services available either. Jane related her experience in trying to get financial assistance for day care and medications:

And ah, so when I ah, it was very expensive. And I thought there's got to be some sort of funding for this. So I get on the phone and I start calling. I called the Office on Aging. They couldn't help me. Then they told me "Well, you call this number". And "Well, we can't help you. Call this number. Sorry". I was hitting a brick wall, every way I'd turn. And I, one day I got real angry at somebody. I think it was somebody over there at the Wheatlands. And I said "What is the Office on Aging supposed to do?" Cause I said "I can't get any help from nobody.

Relational hindering factors included family relational problems, lack of friends, or close relationships with neighbors, friends who had stopped coming by, past patterns of relating to others, and the relationship between the husband and wife. Several wives

had difficulty distinguishing themselves and their needs from those of their husbands. They frequently used the term "we" when describing something that had happened to only one of them. They stated their husbands "would die" if they were not with them. Sue described this situation aptly when asked about having people come to help out:

I just don't want them to. Ah, he would not be, I always said if he was a Siamese twin attached to me he would be great. My daughter was recently here and she said she noticed he was more agitated if I was not here, inside.

Suggestions by friends to place her husband in a nursing home especially horrified Sue as she stated:

You know, his dear friends just told me to put him in a nursing home and I think that is so cruel! I just can't.. and telling me that. And what kind of life would I have? That's the main reason I don't. Well, no, not the only reason, but I wouldn't have any better life if he was in a nursing home. So, that makes no sense to me.

Family relationship problems were often a hindering factor to getting help from family members. Jane described family relationships that were not close as hindering factors to getting help from her family:

That ah, because they'll say "Well, when was daddy diagnosed?" You know, and ah, they know as well as I do when he was because they were down there when the doctor told him, told us that he had Alzheimer's and he could no longer drive. But I don't think they are aware that caregivers do need some time for themselves... The two that live here, they do not help. They do not help. They say "Well, we can't."

The largest situational hindering factor that prevented wives from making choices to reach out to informal sources was the perception that family members, friends, neighbors, church members, pastors, and others were too busy to be able to provide any assistance. Charlotte shared her perceptions:

I hate, cause everybody's got a life and people today are so busy. The more things you have to do, the busier you are. You just, you say, well, they say "Call me any time." But then I know, you call them, they say "Well, I had a hair appointment today, but maybe I could, maybe I could cancel it and help Marvin." And I just hate that! You know, I just don't want to do that.

Other situational factors included family finances, distance, convenience, and the fact that many of the caregivers' friends and neighbors were also elderly and in poor health themselves. Caregivers related numerous incidents of friends dying or becoming incapacitated. Marie shared one such experience about a friend who used to help her:

Well, um yes, we share a lot. Specifically, both of us like to garden. And ah, she can't. She fell and broke her hip and then after she got recuperated from that, fell and broke her back.

Many situational factors affected choices not to use formal help sources.

Distance, expense, availability, convenience, and accessibility, to name a few, were discussed by wives as deterrents to seeking formal help. Most wives did not want to attend support group meeting during evening hours. Requirements for scheduling of day care center services were not always convenient or feasible for wives. Laura related her problems:

They say you should arrange for it like two days a week or one day a week. They can't just take it on, like if I said "Oh, tomorrow I wanna go somewhere, can you take him?" They have to know. It has to be steady...Course I'd have a hard time especially when I move getting him here cause its a little ways down. Because it takes me a good three hours in the morning ah, to go get him up, get the eye drops in, fix his toenails, get him dressed.

The single largest situational factor that acted as a hindrance to formal service use was spousal reluctance. Many wives stated they would have used services if they thought that their spouses would accept them. This included day care or having others

come into the home to assist with care or household needs. Ellen described her husband's reluctance and how it prevented her from using adult day care:

But ah, he don't want to go back there again. And boy that was nice! Well he says that they sit in a circle and do things, you know, keep their minds busy, which I think they should do. But ah, he, he just won't go back there again, And I felt so bad! ... see the bus come right here to the house and picked him up and brings him right home. And I hadda pay for that, but I didn't care about that. Ah, they were so nice on Wallace Street Senior Citizen Place!

Experiential hindering factors were a major deterrent to choices by wives to reaching out to others for help. Given the fact that most wives were reluctant to bother people and ask for help to begin with, if a wife was rebuffed or turned down once, she was very likely not to ask for help from that source again. Sue related such experiences:

Well, I've had some experiences. So actually I did ask once and they weren't available. And it was sort of an emergency type situation. And I think I asked two. I didn't tell them specifically what I wanted, but they weren't available. So I just don't think that I would do that. I mean, I just think that when it comes time to, I need help that, I need to get professional help. And I don't need to depend on anyone I know.

Poor experiences with health care professionals and medical care made the wives in this study reluctant to utilize such services. Unfortunately many such experiences were told by these wives. In cases where hospitals were involved, the caregivers had no choice if future circumstances dictated such services were needed, but where choices could be made, wives chose not to use those services again. Wives told of long waiting periods to get services, unavailability of help from agencies, inability to reach agency representatives when they called, and a general lack of satisfaction with the overall medical system. They described wrong and improper medication being given to their spouses, lack of attention to symptoms and problems, and lack of knowledge

regarding care of persons with dementia. Betty related an instance when she put her husband in a facility for respite so that she could take a vacation:

We could not go back down there. It was not what an Alzheimer's, what I think an Alzheimer's unit should be! They told me he didn't sleep in his pajamas. Well, he does if you help him get them on. If you just say "Go to bed" he'll go in his shoes and all! And apparently that was the kind of care he was getting. And ah, Justin was really upset. She said "Mama, they're not taking care of daddy."

While there were few hindering factors that affected wives choices to reach within and manage by self, there were many hindering factors that affected wives choices to reach out to either informal or formal help sources. Internal hindering factors affected both informal and formal help choices. Relational hindering factors affected primarily informal help choices. Situational and experiential hindering factors affected both.

One exception where presence of hindering factors made no difference in decisions to reach out consistently emerged from data analysis. This was in cases of emergency. Extreme spouse or caregiver need could supersede any number of hindering factors. As Helen aptly stated when discussing reluctance to seek outside help:

When, when there's an emergency absolutely not! If there's an emergency, I'll call and yell from the roof top if necessary!

Action/Interaction Strategy: Making Choices

The action/interaction strategy that emerged from data analysis was making choices. Specifically, wives made choices to use patterns of avoiding, shouldering, or facing to reach out or reach within to manage care for their husbands and day to day

living needs. These choices of patterns varied on a day to day basis in response to caregiver and spouse needs and facilitating or hindering intervening conditions.

Avoiding. Avoiding was an early pattern used by wives in the initial stages of the spouses' dementia. The avoiding pattern was used by wives to manage by self. Although the women related feelings of unease regarding early behavior of their husbands, they attempted to explain these feelings away by attributing the behaviors to other factors such as normal aging, stress, and other medical conditions. Sue related how she interpreted her husband's behaviors:

Well, you know, ah, the older you get, the more sometimes that you tend to forget. But I noticed that he started making himself little notes: Well, I've got to go here and here and here tomorrow. And I've got to do this, this and that. he would just make his little notes. Well, I never thought anything about that either. And, but sometimes you know, I do. And I've got a calendar. I've got to keep everything down even for myself. So I never thought anything about that.

Avoiding behavior gradually diminished as the spouses' conditions progressed to a point where they could no longer be ignored and medical help was sought for a diagnosis. However, this pattern frequently resurfaced as wives minimized the seriousness of the relational and behavioral problems that they were experiencing with their husbands. Abnormal almost became normal in their daily lives. Ellen related:

The way Albert is, I can manage him and take care of him because I think he is not getting too bad yet. But I can tell when, if he does get real bad. But he gets his temper. But he gets over with it. But he just doesn't remember and he hides everything. And then his long johns, he cut all the bottoms off on them. Oh, he took his long johns off and he ripped them all up. He cut them all up. Yeah, that's his own clothes though, not mine.

Avoiding as a means of coping, helped wives to maintain a semblance of normalcy in their lives, a way to continue to see their husbands as they once were and

their marriages as being the same. Jane described how she used avoiding as a way of coping:

And I kept telling myself, well, its not Alzheimer's. They don't know what they're talking about because this man is perfectly normal! When all the time I, I knew, but I just did not want to accept it. Because that is a very bad thing, you know, to come to accept (tears in eyes). Cause here, you know, you marry this real strong man that has worked all of his life, and um, active, and um, exercised, walked. And ah, all at once, you know, you see this man.. you don't know him!

Avoiding also took the form of failing to make plans for the future. Wives spoke of taking one day at a time and not planning for an uncertain future or for future events that they hoped would never happen. As Margaret stated:

We had a couple friends. One ah, was a very dear friend ah, who had Alzheimer's. And she was put on oh, tube feeding and she just laid there for years! And I do mean years! And she didn't know the world she was in, I do hope and pray that its the Lord's will that we won't have to go through that.

Jane responded to a question about future plans with this statement:

I'm managing and you know, I'm just coping. I'm just one day at a time. That's all I can do. And I make no long range plans. And, cause I never know from one day to the next... Like I said, I just really don't think a great deal about the future. I'm just taking everything one day at a time.

Avoiding was the pattern that was heavily used by wife caregivers early in the trajectory of the spouse's disease. Use of this pattern usually tapered off to occasional use in the forms of minimizing and lack of planning for the future as the caregivers adjusted to the illness and change in role. Shouldering became a more prominent pattern as avoiding diminished.

Shouldering. Shouldering was also a pattern used by wives to manage by self. It involved taking up the burden and relying in internal resources for care of husband and

household. Shouldering took the forms of coping, managing, doing, adjusting, medicating, working around, taking over, and other multiple means of assuming the burden for day to day activities. All the wives, including those who were also utilizing informal and formal help used the strategy of shouldering. Most wives used shouldering to a high degree of intensity, for long durations of time, to a heavy extent, and frequently, no matter how much informal or formal help was received. Glenda described how she still shouldered responsibility for her husband at night even though she had hired a sitter to stay nights:

Well, see this help that stays the night, works eight hour shifts during the day. And so she's tired at night you know. But that's what we hired her for. and ah, I caught on. I didn't catch on at first. But I kindda caught on. Cause if I, I'd just think well this is foolish for me to be getting up too.

Wives refused to get outside help when they felt they could manage by self. They related many instances when help was offered or suggestions were made to get help, but they refused, preferring to shoulder the care by themselves. Ellen simply stated:

A lot of people told me I could get help, but I can do it myself. Handle it myself. So unless something happens to me, you know, then I don't know what they'll do with Albert.... But Mona says "Oh, Ellen, you've got to put Albert away. You got to put him away. I know, but I still want him around, This way he can talk to me and I talk to him, He (laughs) talks a little goofy to me, but I laugh at him when he's talking to me, you know.

Multiple instances of shouldering were related by the wife caregivers. The wives learned as they went along, using methods like hiding things, counting birds, taking keys, stretching the truth, locking doors, watching, and many others to manage the behavioral problems and complexities of caregiving. Throughout the caregiving

experience wives made the choice to assume the majority of care by themselves utilizing patterns of shouldering. Shouldering was present at all stages of the caregiving experience.

Facing. Wives made a choice to use facing patterns when they reached out to informal or formal help sources. Some wives were using multiple informal and formal help sources. Other wives were using very few. Specific facing activities included talking, calling, looking, telling, paying, contacting, attending, taking, fighting, praying, asking, and many others. Helen described how she reached out to friends by calling:

And ah, mostly they initiate the calling. Ah, but usually its like if I have Sunday School business, and I'll call them up. And we'll start talking and then we'll get into that. Because the ones I talk to are also ah, officials in the class have all lost their husbands.

Charlotte told of calling a geriatric assessment program to get information on resources to help her:

So then I called there last week and I said "I want to get in touch with where I can get some caregivers or some support group, some whatever." And she sent me a paper the next day. So I have it.

Glenda took her husband to a special clinic for treatment of his Parkinsons:

So we did that. And that's what we've done now. We've been going down there for the last six months. And ah, we'll go back again in December. And ah, they say that really and truly there's not a whole lot that they could do for him cause he's had it so long, you know. Its probably not going to do him much good, but anyway, they've given him some medication for the memory. And ah, he seems to be improving on that.

Facing also meant paying for help from a variety of formal help services. Laura talked about paying for help:

I've been in business all my life and I pay for a lot of things I can't do for myself. And things I can't do for myself I get somebody and I pay them to do it. And they do it graciously and I'm not yelling at my neighbors to come and help me every time I do something.

Making plans for the future was also a part of facing. These plans included settling business such as making out wills, determining power of attorney, getting insurance, and planning for equipment to handle care. Betty related the plans she had made:

And ah, I have gotten ah, although I have never wanted any life insurance on me, I want to be worth more alive than dead. And I got a life insurance policy in order that should something happen to me, the kids can take care of their dad with that without having to sell the farm. And then knowing how much effort it is to take care of somebody, I've got my home nursing, nursing home policy for myself.

When caregivers made a choice to use facing, they acknowledged the need to reach out to others for assistance and did so. Facing coexisted with avoiding and shouldering during the caregiving experience and varied according to caregiver and spouse needs and the presence of hindering and facilitating conditions. The result or consequence of making choices to reach out or reach within was continuing care.

Consequence: Continuing Care

The consequence of making choices was continuing care. This care at home for the husband was continued at lesser or greater cost to the wife depending on choice of action/interaction patterns used and effectiveness of help received. Continuing care with less cost occurred when patterns chosen proved effective in assisting wives to manage care. Continuing care at greater cost occurred when patterns chosen were not effective in assisting wives to manage. Reduced emotional, physical or financial burden were the

results of effective pattern choices. Increased emotional problems, physical or health problems, or financial loss were results of ineffective patterns choices.

Consequences of avoiding. While avoiding patterns initially allowed wives to cope and maintain patterns of normalcy in their lives as previously discussed, they eventually became ineffective. Wives realized that avoiding patterns were ineffective when the reality of the situation and deteriorating condition of their husbands could no longer be ignored. Sometimes this realization came at great cost as in the case of Helen who described her situation:

And it was ah, he really didn't remember. And ah, very common place things, And ah, but I didn't have any idea then, you know, back ah, back then, that far back.... I asked him ah, "Don't you want me to help? Don't you want me to write some of the checks?" And ah, he would, would have a little tantrum. And ah, and then, one time, I know, he just said "Well, you just take it and do it. See if you can do any better". And I said "Well, do you want me to?" And ah, at any rate, I should have stepped in right then. But it was only when that happened another time, several months later, and ah, and he actually tossed the checkbook down on the desk and said "You do it if you think you can do better."... And ah, that when I got in, in to um, accounts and so on, which I had no knowledge of, and found out that they were terribly a mess! ...So, ah, and we don't have as a result of many things, but basically not knowing the situation, we just don't have anything, except what comes in each month.... Don't have any savings.

Consequences of shouldering. There were few positive results of choosing patterns of shouldering reported by wife caregivers. The few instances that were related included maintaining independence and satisfaction of the spouse and wife with the wife's ability to maintain pre illness patterns as much as possible thereby keeping the relationship intact. Betty related her feelings about this:

But ah, for my sake, I would rather him be at home. As long as he's being capably cared for....So that's the, and we're in a situation where we can stay out in the country where he likes it. And he'll sit and think what a great place it is. He likes it.... So he's satisfied where he is and it means a lot to him, to the

family as well....Nobody takes care of them like you think they ought to. I think that's one thing we should realize. Do as much as well as you can as long as you can and when you can't do it any more, you turn them over to somebody else.

Numerous negative effects of choosing shouldering patterns were reported in this study. Wives who were choosing frequent shouldering patterns of high intensity, long duration, and heavy extent reported the most negative effects especially when spouse or caregiver needs were also high. Continuing care at greater physical and emotional cost was reported with regularity by these women. Ellen reported how continually managing her husband's behavior problems affected her:

Because, I gotta holler at him. I gotta talk to him: "Albert, please don't spit." Augh (makes face) That gets me. And I get so depressed, especially in the winter time was awful... Yeah, its sad. Its hard. Especially for you to be doing this.

Many wives reported feelings of mental exhaustion, physical and mental fatigue, or no energy. Glenda shared how she felt most days:

Well, I, you know, I've been, I guess its just ah, ah, fatigue, a lot of it. And ah, you worry (tears in eyes).... Well, some days its good, and some days bad.... Its just that its so many things to do. And ah, things that he wants me to do in his way.

As the husband's conditions deteriorated and they were less able to interact socially, many of the wives also reduced their social contacts to spend time with their husbands. Also as husbands became less able to relate, often friends stopped coming by, further isolating the couples. If the choice was made not to reach out, isolation was a frequent negative consequence reported by wives who had chosen to rely heavily on shouldering patterns. Marie related the following when asked about her social contacts:

Well no, not any more. We go to the childrens', and even he doesn't want to go to the childrens'. He would prefer them coming here. But ah, um, we were talking one day and I said something to him about all his friends and he said

"What friends?" Says "They're all dead." And ah, they, we have a man up the street that he was friendly with, but he just honks when he passes. Never comes in.

Helen described an emotional aloneness that occurred to her as she chose patterns of shouldering care for her husband:

Because to see ah, you can say the thing you love most in the world, disappear and not only disappear, but go through such horrible trauma, and ah, not having anybody who really understands.... If they saw it a little more graphically than they do, you'd know you're not quite that much alone. But ah, there needs to be, there needs to be some way, well, that's the kind of thing that each family would have to work out for itself.

Helen further related how her choice of shouldering patterns and not reaching out to family and sharing problems with them caused family tensions:

Well it was, it was difficult. And they didn't, there was a time, I think, maybe for a very short period, because of my natural disposition and their father's natural disposition, um...And ah, there was a time when there's absolutely no question that ah, they blamed me for ah, for some uncomfortable times, ah, that they couldn't comprehend. And I didn't have the sense to explain to them.

Consequences of facing. Choosing patterns of facing where the wives reached out to others for help resulted in both negative and positive consequences and therefore less or greater burden depending on the response of others to the wives' reaching out and the quality of help received. When wives received the help they needed as a result of using facing patterns, care was continued at less physical, emotional, and/or financial cost. However, if the response to requests for help were ignored, not adequate, or if barriers existed to getting to the help, care was continued at greater cost because wives had to fall back on previously ineffective patterns of shouldering, or expend more time and energy attempting to get help.

Many positive consequences of patterns of facing were reported. Wives described relief and the ability to relax as common responses to receiving help from others. Sue related one such experience:

When my daughter came in, I didn't realize how tired I was, mentally. And she just took care of him and I would be outside working with my neighbor. And it was, it was, oh, it was such a relief! I didn't have to think about him. And I knew he was well taken care of. So that will refurbish my mind, maybe refurbish me.

Using facing patterns to reach out to tap spiritual beliefs and religious faith resulted in many positive emotional consequences for caregivers. Wives spoke of not being able to get by without their faith and of how faith and beliefs had given them the strength to continue care. Margaret shared how she received help from this source:

Oh, I definitely think so. I don't think I could, I don't think I could do it without that. I think I've been given strength to ah, to do what I have done. And I just ask for ah, guidance on what to do. And ah, I think it will come. It seems like its, it seems like its taking quite a while, but I do think it will come. One way or another.

Marie described how her faith gave her hope for the future:

Oh absolutely, you couldn't, I don't see how people do it if they have, didn't have faith. But I think that most people have faith. really and truly I do. Ah, I think anybody that has hope has faith. That's my belief now.

Belonging to support groups either physically or on-line helped caregivers develop a different perspective on their problems and reduced the burden of caregiving allowing them to continue care at less cost. Jane described how this helped her:

Um, sometimes I think I have it bad until I read, you know, what other people in their letters are saying about their ah, loved ones, and the shape that they're in, and the hassles. And here I am complaining! I have no complaints. I'm really ashamed of myself.

Physical burdens were reduced as the result of obtaining help through using facing patterns. This allowed the caregivers to continue care at less cost. Anne described how home health relieved her:

But of course the home health girls come in and then the nurses come in. And so, ah, so that, that's a lot of help really. Relieves me a lot that I would have to do if they didn't come. And so, I think, I've done pretty good.

Negative consequences of facing patterns were cost of formal care, not all of which was covered by insurance or Medicare, and loss of independence. Helen stated:

I think that what's gonna happen is that I'm going to be less independent. But I ah, I know I'm going to become more dependent and more aware of, more aware of ah, the outreach of people. Because many, many more friends are reaching out and ah.... But ah, its just simply is only, very recently, hitting me that I've got to have help.

Other negative consequence of using facing patterns to reach out included bad experiences with formal care or when friends, neighbors, or family were asked. These situations have been previously identified and illustrated in the section on hindering intervening conditions since these negative experiences feed back into that portion of the model. These hindering or facilitating conditions then, again affected choices made by caregivers.

Continuing care at greater cost fed back into help needs of caregiver or spouse and provided impetus to make new choices to again reach out/reach within through use of the action/interaction strategy patterns of avoiding, shouldering, or facing. Reduced cost of continuing care did not necessitate a change in choices of patterns or adjust of

the relative proportions of reaching out/reaching within that the wife caregivers were using.

Substantive Model

The descriptive story was translated into a substantive model and the new theory of Help-Seeking Choices: Taking One Day At a Time is diagrammed in Figure 4.2. This model incorporated the paradigmatic model and added density and complexity by showing process. By adding process to the diagrammatic model sequences of action/interaction were linked as they pertained to the management, control over, or response to reaching out/reaching within. The linking of sequences was accomplished by noting (a) change in conditions influencing action/interaction over time, (b) the action/interaction response to that change, (c) the consequences that resulted from that action/interaction response, and (d) describing how those consequences became part of the conditions influencing the next action/interaction sequence (Strauss & Corbin, 1990). Building of process into the analysis assured that the grounded theory that evolved was a dynamic theory rather than a static one.

The Theory of Help-Seeking Choices: Taking One Day at a Time

The proposed theory asserts that once older wife caregivers of husbands with dementia come to a realization that a problem exists, they utilize both reaching out to others and reaching within themselves simultaneously in varying proportions at any given point in the caregiving experience to manage care of their husbands and households one day at a time. The relative proportions of reaching out/reaching within, and more specifically, managing by self, involving informal help, and involving

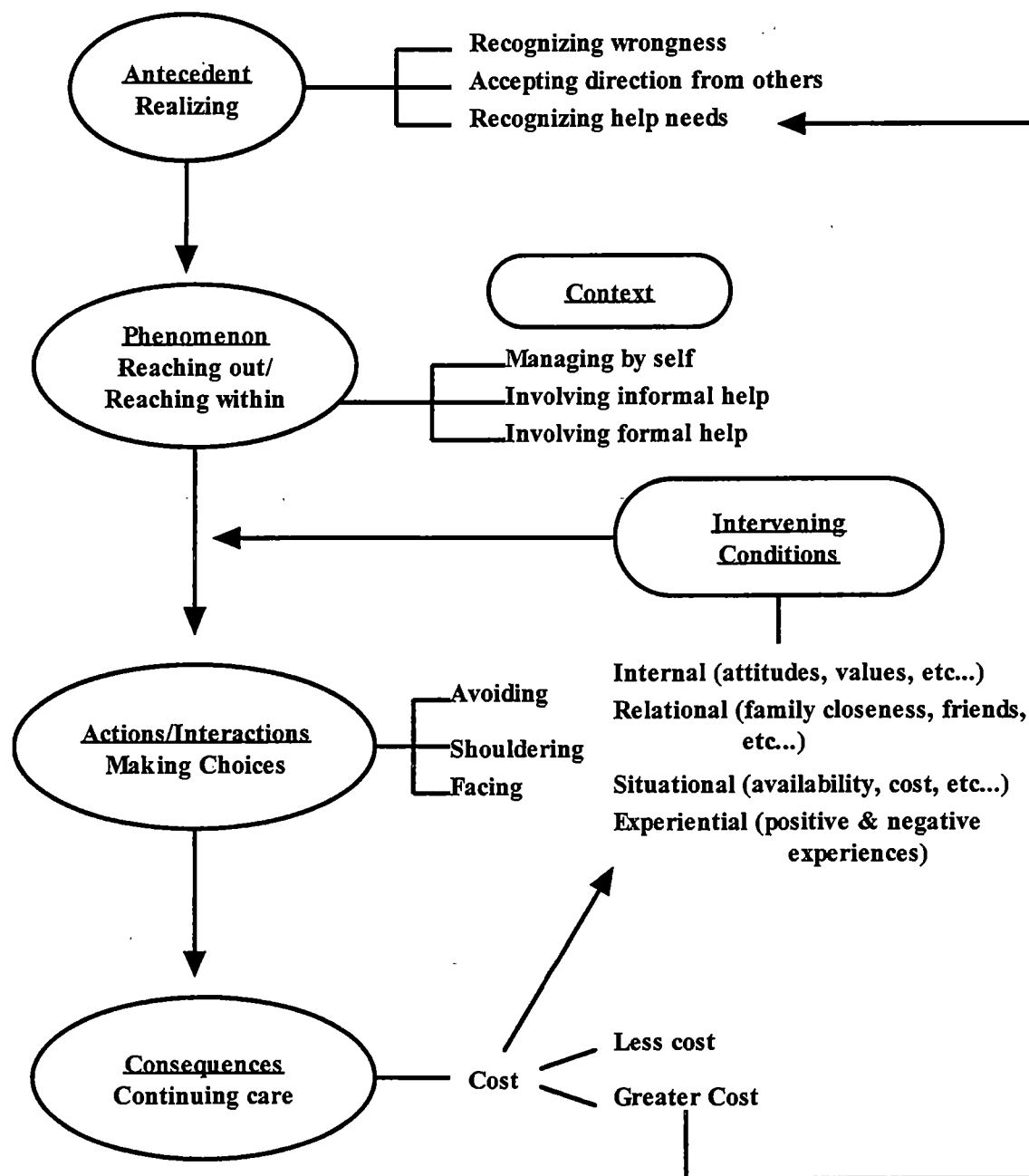


Figure 4.2 Help-Seeking Choices: Taking One Day At a Time

formal help, varied based upon a multiplicity of intervening conditions which either hindered or facilitated making specific choices and also upon the wives' perceptions of their own needs and needs of their spouses. Reaching out/reaching within evolved and changed through wives making choices among three dynamic, interconnected, and often overlapping behavior/relational patterns or interaction/action strategies which were avoiding, shouldering, and facing. Evolution through those patterns was not linear, but rather a cyclical process that varied in response to the changing complexities of the caregiving situation and in response to consequences of previous pattern choices. Use of the behavioral/relating patterns of avoiding, shouldering, or relating allowed the wives to continue caring for their husbands at home at either less or greater cost to the caregiver. Consequences of making choices fed into hindering and facilitating intervening conditions affecting future choices. Consequences also fed into caregiver or spouse needs thus beginning the process anew to reach out/reach within by making choices. Integration of patterns that emerged from data analysis of the experiences of these women in managing care for their husbands resulted in the identification of the possible consequences and determining situations listed below:

When wife caregivers realize that a problem exists with their husbands that may require help, they respond by reaching out/reaching within and managing by self, involving informal help, or involving formal help through making choices of patterns of avoiding, shouldering, or facing.

- If avoiding occurs at high levels, negative consequences in the form of continuing care at greater cost may occur.
- If shouldering occurs at high levels and spouse needs or caregiver needs are extensive, care will be continued at greater cost
- If shouldering occurs at high levels, but spouse or caregiver needs are not extensive, care will be continued at no change in cost.
- If shouldering occurs at lower levels in conjunction with facing to obtain help from other sources, care will be continued at less cost than previously.
- If avoiding occurs at low or sporadic levels care may be continued at less cost.
- If facing occurs at high levels and help received is effective, care will be continued at less cost.
- If facing occurs at high levels and help is not effective or unavailable, care will be continued at greater cost.
- Where hindering intervening conditions are present, chances that a wife will use a particular pattern are reduced.
- Where facilitating intervening conditions are present, and help needs are extensive, chances that a wife will use a particular strategy are enhanced.
- A wife will usually reach out in an emergency situation regardless of hindering conditions.

All consequences, and determining situations were substantiated by the data. Exceptions could possibly occur, but such incidents were not related by the wives in this study. The theory of Help-Seeking Choices: Taking One Day at a Time is useful in possibly predicting some of the consequences and determining conditions of help-seeking in older wife caregivers of husbands with dementia. More importantly however, the theory informs us about the process of help-seeking in these women and the influence of relationships in the cycle of making choices related to help-seeking. The theory is substantive in nature because it was generated for a specific, circumscribed, and empirical area of inquiry and was studied at the interaction level of the conditional matrix. Examination of this phenomenon under a variety of types of situations and at different levels could result in development of a formal theory.

Summary

The theory of Help-Seeking Choices: Taking One Day at a Time emerged from the findings of data analysis of eleven wife caregivers' experiences with help-seeking to manage care for husbands with dementia. A single dialectic core category which represented the basic social process of the phenomenon under study was identified and named reaching out/reaching within. Substantive theory development was aided by use of a paradigm model as outlined by Strauss and Corbin (1990). The theory was validated against the data to complete its grounding and is faithful to and illuminates the process of help-seeking for this particular group of caregivers.

CHAPTER FIVE

Discussion, Conclusions, and Recommendations

The purpose of this study was to gain an understanding of patterns of help-seeking by older wife caregivers of demented husbands. The substantive theory of Help-Seeking Choices: Taking One Day at a Time, that emerged from this study of older wife caregivers of demented husbands provides much needed illumination of help-seeking patterns for this population of caregivers and contributes to nursing's body of knowledge regarding this phenomenon. Rather than focusing on service utilization by these caregivers which has been much studied but continues to be poorly understood, this study explored the more basic process of help-seeking which is essential to understanding service utilization patterns of caregivers. Grounded theory methodology and a nursing theoretical framework, Newman's Theory of Health as Expanding Consciousness (Newman, 1986, 1994), provided a means of exploring and interpreting the experiences of wife caregivers and identifying patterns of interactions in development of this theory. This chapter is organized into the following sections: (a) discussion of findings, (b) examination of the findings in view of Newman's Theory of Health as Expanding Consciousness, (c) conclusions, with implications for nursing practice, education, and service systems, and (d) recommendations.

Discussion

Eleven older wife caregivers of husbands with dementia were asked to tell their stories about seeking help and managing care for their husbands at home. An initial open-ended question of "tell me about a time that you felt you could have used help in managing care for your husband" was followed by more specific, probing questions as each participant's story emerged. Each participant's story was unique, and each had her own struggles, problems, strengths, and fears, but there was a commonality of experience throughout these stories and common patterns that identified the essence of the collective experience.

All the wives in this study were continually adjusting, on a day-to-day basis, both reaching within themselves to tap inner resources, and reaching out to others for help, in order to manage care for their husbands. The wives made choices daily, based on a multiplicity of factors to use strategies of avoiding, shouldering, or facing in order to reach within or reach out. The process of making these choices and reaching within or reaching out was precipitated by a realization that there was a problem that required some type of action. Many intervening internal, relational, situation, and experiential conditions influenced which strategy a wife would use or the degree to which a particular strategy was utilized. The consequence of making these choices and reaching out or reaching within was the ability to continue to care for the husband at home. Depending on the effectiveness of the reaching out or reaching within, this care was continued at greater or less cost physically, emotionally, or financially to the wife.

Experiences with seeking help fed back into intervening conditions influencing future decisions to seek help. Increased cost of caregiving fed into increased need which was recognized by the wife and acted as an antecedent to beginning the process anew.

This study supports previous help-seeking research by revealing the importance of realizing to the process of help-seeking. The importance of realizing is evidenced by its placement as an antecedent in the theory. Wives in relating their stories repeatedly told of delaying the seeking a diagnosis of dementia for their husbands. In many cases, the wives were aware for years that something was wrong, but they continued to try to ignore what was happening and hoped it "would go away". Descriptions of behavior of this type are consistent with what has been reported in the caregiver literature (Haley et al., 1992; Phillips, 1990). Even after the diagnosis was obtained, wives tended to minimize the problems they were experiencing, lending support to the concept of "survival denial" identified by Veroff (1981) which described older people's likeliness to deny that problems are too difficult to handle. The fact that in some cases it took the direction of other people such as a physician, priest, or family member to precipitate a recognition of wrongness or initiate help-seeking, supports work done by Gwyther (1989, 1990) which indicated that caregivers might need permission or direction from others to seek help. Further, many of the participants also had difficulty recognizing the magnitude of the caregiving burden on their own well-being or recognizing the need for help supporting other research in this area (Cohen, 1997; Davies et al, 1994; Szabo, 1997).

The multiplicity of intervening conditions which impacted upon the choices made by wives whether they would manage care by themselves or involve informal or formal help are an important finding in this study and support much previous research regarding the impact of attitudes, availability, time, cost, and other variables on help-seeking and service utilization (Berry et al, 1991; Fortinsky & Hathaway, 1990; King et al, 1995). Wives in this study related desire to remain independent, family conflicts, difficulty with accessibility, cost of services, time involved getting spouses ready, and dislike of indebtedness as some of the intervening conditions that affected decisions regarding help-seeking. These intervening conditions assumed importance in making decisions concerning what type of specific help the wife would seek and were not as important a consideration when wives made decisions to seek help as was the realization that help was needed. Bad experiences with seeking help, either people or services not being available or of poor quality, determined whether wives would seek help from those sources again. This supports previous research indicating that individuals use social support networks to the extent that they perceive those networks as being available and responsive (Knisely & Northouse, 1994)

While many studies have addressed use of formal and informal resources by caregivers and decisions to use those resources, no study to date has described the reaching out/reaching within phenomenon revealed in this study which provides new information in this area. The reaching within portion characterized by managing by self was always present in the caregiving experience no matter how much reaching out was occurring. It was continuously being balanced with reaching out and involving informal

and/or formal sources of help. Previous research has neglected to address both components as a simultaneous phenomenon thus failing to recognize the dialectic wholism of this component of the help-seeking process.

The wife caregivers' reports of negative consequences of prolonged, intensive caregiving are consistent with current caregiver burden literature (Alzheimer's Association, 1996; Haley et al., 1987; Gottlieb & Gignac, 1996; Stone et al, 1987) . Physical negative consequences reported in the interviews were increased health problems, fatigue, and lack of sufficient rest. Psychological negative consequences were depression and high stress levels. Social negative consequences were reduction in social activities, isolation, and restriction of pleasurable activities. Lack of family closeness and support for the wife caregivers was reported as being particularly distressing, supporting what has previously been reported regarding family conflicts and caregiver depression (Semple, 1992).

Support of research showing caregiver loss of self and role engulfment (Skaff & Pearlin, 1992) were also apparent in this study. Several of the wives frequently used the noun "we" to describe either the husband or the wife. The wives who were having problems distinguishing themselves as separate individuals, also seemed to be utilizing more managing by self, be experiencing more difficulty making decisions by themselves and were reporting more difficulty in reaching out to others, particularly for care of the husband.

Monahan et al (1992) reported that age was a predisposing factor to caregiver attendance at support groups with older caregivers showing greater attendance. It would

be expected then, that since all wives in this study were age 60 or older, support group attendance would be high. However, of the wife caregivers in this study, only three were attending any kind of support group. Several others had attended one or two times, but did not find the groups to be helpful. This aspect will be discussed in the section on implications.

Previous research findings of patterns of service utilization, or more specifically patterns of underutilization, delayed utilization, reluctance to utilize, and inappropriate service use, were all supported by this study. No studies to date however, have reported use of 911 or police as regular sources of help for dementia caregivers. By illuminating this new information, this study has contributed to knowledge of emergency service use by wife caregivers of husbands with dementia.

Specific action/interaction strategies of avoiding, shouldering, and facing are new findings emerging from this study. Current literature has not addressed the avoiding behavior that occurs with caregivers in response to the caregiving experience. Neither has the shouldering aspect been much explored except as incidental information. When placed within the new theory, the importance of these strategies, and the cyclical progression through use of these strategies provides a more comprehensive view of the help-seeking process.

Overall, most of the current findings in caregiver, help-seeking, and service utilization literature were supported in this study. Additional insight into the actual process of help-seeking has been gained through this study by examination of help-seeking patterns by the wife caregivers. New insights into the importance of realizing

that there is a problem, the dialectic nature of reaching out/reaching within, the impact of intervening factors on making choices, and identification of action/interaction strategies of avoiding, shouldering, and minimizing contribute new knowledge to what is already known. Most importantly an understanding of the entire process as an evolving pattern provides a new perspective of help-seeking. A discussion of the findings within Newman's Theory of Health as Expanding Consciousness is the next section of this chapter.

The Theory of Health as Expanding Consciousness

Within the Newman framework, the disruptions in the lives of the wife caregivers that have occurred as a result of the husband's dementing illness are viewed as "choice points" (Newman, 1989). These times in a person's life can be viewed within the theory as opportunities to experience more fully the reality of one's life patterns and experience expanded consciousness. Choice points occur when one realizes that old ways of living, relating, and doing things simply don't work anymore. Numerous examples of avoiding, and shouldering patterns demonstrated how the wives continued to use old patterns that simply weren't working anymore, resulting in increased physical, emotional, and social problems. However, many of the wives continued to utilize those patterns with high frequency, attempting to maintain "normalcy" of the relationship with the spouse and others. The stresses of the caregiving experience were forcing these wives into trying new ways of relating to others in order to obtain the help they needed to continue care and thus move them to new patterns of expanded consciousness.

According to Newman, freedom to come and go as one pleases is taken for granted until one no longer has that freedom. When one's movement is restricted, as in the case of the wife caregivers who were becoming increasingly bound to the home and caregiving, the "restriction of movement forces one into a realm beyond space-time... One is confronted with one's own inner resources, the quality of one's relationships, and one's ability to live in the present" (Newman, 1994, p.60). Thus, restriction of movement was also forcing the wives to relinquish old patterns and discover new ways of relating thereby expanding their consciousness.

The nurse researcher during this study was interacting with the participants at choice points in their lives. Chaos, disequilibrium, and disorganization related by the wives was indicative of this point in their patterns as the wives learned new rules and were in the process of being transformed in the movement to higher consciousness. The unfolding pattern of the quality of relatedness with their environments, characterized by forming of new relationships with family, friends, neighbors, church, and a higher being for the purpose of assisting the wives to continue to manage care of their husbands could be viewed as expanding consciousness. Several of the wives told of the transformative nature of this process by sharing instances where they had done things they never would have considered doing in the past. They discovered new strengths within themselves and new ways of relating to others.

When the nurse researcher shared the new theory from this study with the wife participants, wives verbalized insight into their patterns. This insight or pattern recognition, according to Newman is essential for opening up the possibilities of action

and interaction to move beyond limitations that are available to the person (Newman, 1999). Pattern recognition actually began when the wives were relating their stories as many made statements that they had never realized they acted or reacted in certain ways until they were relating their stories to the researcher. Many wives requested information or assistance with accessing services either after the interview or in follow-up, with the nurse researcher. Information and assistance was provided as requested. Also wives related how they found the interview to be of therapeutic benefit to them. In this way, research became praxis as described by Newman (1990a).

The patterns for these wives continue to unfold. The wives in this study had not yet transformed to a higher level of consciousness. Some were farther in the process than others. All were in process of transformation, hence the disequilibrium continues, as these wives explore new ways of relating, discarding those ways that do not work and trying new ones to replace the discarded. Findings of this study then, contributed to and supported the Theory of Health as Expanding Consciousness thereby contributing to a body of knowledge that is specifically nursing's.

Conclusions

This study illuminated the help-seeking process for a select group of older wife caregivers of demented husbands. A new theory of Help-seeking Choices: Taking One Day At a Time emerged from data obtained from the experiences of the participants. While the theory is specific to older wife caregivers, there are implications for nursing practice, nursing education and health care systems which should be considered.

Nursing Practice

This grounded theory arose from analysis of patterns of interactions of wife caregivers of demented husbands. Identification of patterns and the sharing of those patterns with the caregivers opens up the possibility for action and facilitates decisions of caregivers to act for themselves or on behalf of their relatives (Yamashita, 1998). Nurses need to recognize the chaos of the caregiving situation as a choice point and be with caregivers in an authentic way for the purpose of interaction and pattern identification that can lead to new ways of interacting and thus expanding consciousness in the both caregiver and nurse. Once pattern identification occurs and the caregiver realizes new possibilities, the professional nurse, acting as a case manager can assist the client in implementation of their decisions no matter what they are.

Nurse case managers can assist with brokering resources and services and with referrals if this is what caregivers want and need. It is important for nurses working as case managers or in areas where referrals are made, to be aware of services that are available. Through assisting with early pattern recognition nurses can enable caregivers to seek appropriate assistance earlier in the caregiving experience thereby incurring less cost of caregiving to the caregiver and assuring the ability of the caregiver to continue care.

Within the new theory, realizing that there is a problem is an important antecedent to the help-seeking process. Often this realization comes much too late and after much cost has been incurred. Elders as a rule, see health care professionals on a frequent basis because they experience more chronic illness than younger adults, and in

fact spend an average of 10% to 15% of the last years of their lives with a chronic illness. They are also hospitalized more frequently for acute care (Administration on Aging, 1997). Frequently practitioners focus only on presenting problems and fail to view the person holistically. The nurse can assist with earlier recognition of problems by including cognitive assessment as part of every overall assessment for elders and initiating referrals for definitive diagnosis when problems are noted. The nurse can also assist with problem recognition by sharing observations with caregivers thereby bringing problems into conscious awareness, opening lines of interaction and communication, and facilitating realization of problems.

This study demonstrated the importance of previous bad experiences with seeking help on future help-seeking choices. In these times of cost containment and managed care, nurses need to be aware of the impact of their own performance on future decisions individuals will make and strive to provide quality care with "care" being the operative word. It is also essential that nurses in geriatric settings have an awareness of the latest research findings in their areas in order to provide the best care possible. Family members should not be better informed than professional nursing staff in these matters.

Nursing Education

Medical models of health care delivery are not responsive to help needs of many individuals. Nursing education based on the medical model simply compounds the problems that are already present. Nursing education based on caring and pattern recognition is needed. Meaning must be recognized as an important element to a

person's experience and understanding that meaning is important to understanding persons and their experiences.

This study supports the need for nursing education to place more emphasis on the nurse-client relationship and teaching nursing from a framework that provides an wholistic context for nursing and nursing care, including the centrality of authenticity and empathy in the nurse-client relationship. This relationship whereby the nurse comes together with clients at choice points and through authentic interaction, assists clients in pattern identification and exploration of new possibilities is essential for empowering clients to make decisions that are best for them. Focus needs to be placed on cultivating self awareness, creativity, sensitivity, and mindful attention to others in nursing students. Picard, Sickul and Natale (1998) suggest that centering meditation, journaling, and creative expression be integrated into nursing education experiences to facilitate empathic communication and the ability to harmonically resonate with the inner life of others. Empathy is a pivotal aspect of the nurse-client relationship and new ways of cultivating and encouraging natural empathic abilities in students should be integrated into nursing education (Evans, Wilt, Alligood, & O'Neil, 1998).

Findings of his study suggest that nursing education should include more content on support of family caregiving and caregiver needs. As our nation ages, many more family members will assume caregiving roles. Wives in this study expressed the opinion that few people, including health care workers understood what they were going through. Education regarding the stresses and effects of caregiving would heighten the

sensitivity of nurses working with this population and increase awareness of special problems and needs of caregivers such as depression, fatigue, and isolation.

An additional nursing education implication derived from the study findings is the need for education of more nurses as case managers. Nurse case managers are capable of looking at the whole, combining case management with direct nursing care (Newman, Lamb, & Michaels, 1991). The nurse case manager can assist caregivers in pattern recognition and choices to seek help, but needs education in insurance, discharge planning, managed care, and service systems to better help caregivers access and utilize services once caregivers have made choices to reach out.

Service Systems

One of the major implications for health care systems from the findings of this study is the continued need for public education regarding the availability of services. As reported earlier in this chapter, only three of the wives in this study had received a service directory for their county printed by the respective Areas on Aging or knew that one existed. Even the one caregiver who had called the Area Office on Aging was not informed that a service directory was available. These service directories should not be hoarded like precious commodities, but should be widely available through doctors' offices, clinics, churches, and other areas that elders frequent. Individuals who answer telephones at Agency offices should be offering these directories to persons who call in.

There is a great need for coordination of services and sharing of information among all agencies so that if one agency cannot provide a service, caregivers can be told

who to call. A central information and referral number would be very helpful. Logically the local Area on Aging Offices should be where this service is available.

Although the Alzheimer's Association has been in existence for quite some time, many caregivers were unaware of services and assistance they offered. The wife caregivers of husbands who had a non-Alzheimer's dementia erroneously thought that they were not eligible for assistance from this source. Other wives were under the impression that services were limited to research and support groups. More public education is needed regarding this fine association.

Support group attendance has been proven to be an assistance for many caregivers, yet few in this study attended support group meetings. Elders have special needs that support groups must address if the elders are to attend. Wives related the timing of the meetings to be especially problematic. Evening meetings were definitely a deterrent as the wives did not feel comfortable driving at night. However, they also expressed reluctance at having to drive during heavy traffic times as well. Late morning or early afternoon hours were suggested. Also having some type of care on site for the husband while the wife attended the meeting was a prime consideration. Further, several wives who had stopped attending expressed a desire for concrete help from the support groups. They wanted more than just talking about problems without coming to any conclusions.

Experiences of wives in this study highlighted the need for adult day care centers to be more flexible in order to be responsive to caregiver and care receiver needs. Getting husbands with dementia up and going in the mornings was especially

problematic and created difficulty in getting these individuals to day care. Some centers are already offering expanded services where spouses are picked up "as is", then transported to the center, and bathed and groomed there. More centers of this type are needed. Also more "drop in" type of centers are needed. Once a wife uses the center a few times, she may decide to have the husband attend regularly, but not having to commit to a regular schedule in the beginning would encourage more use.

Another implication arising from this study is that more services for elders need to be expanded into rural areas. Several of the rural wife caregivers lived in areas that offered no home delivered meals and this service would have been especially helpful for them. The service directory for one of the rural counties of residence participants in this study only consisted of 24 pages and many of those pages were advertisements. In contrast, the service directory for the metropolitan county consisted of 213 pages.

Recommendations

This study has provided a new perspective on service utilization through the lens of help-seeking pattern exploration and development of a grounded theory of help-seeking. The theory of Help-Seeking Choices: Taking One Day At a Time is proposed as a substantive theory and further validation through continued research in this area is indicated. Continued research that explores help-seeking by caregivers of demented individuals should provide additional support for the proposed theory.

Validation of this theory through theory testing research is also recommended. Specific areas that could be tested include the importance of realizing as an antecedent in help-seeking, the relative influence of intervening conditions on making choices, and

exploration of the specific action/interaction strategies of avoiding, shouldering, and facing. Also, this study examined help-seeking at one point in time in the caregiving experience. No attempt was made to link the patterns or proportions of reaching out/reaching within with length of time spent caregiving. Further, a recommendation is made for longitudinal studies which examine the theory over time as the caregiving experience progresses.

Application of these findings is limited to closely similar caregiver groups. While wife caregivers comprise one of the major caregiving groups, help-seeking by other groups of caregivers needs to be explored. Further research into patterns of caregiver help-seeking should include other groups of caregivers such as husband caregivers, younger caregivers, non-Caucasian caregivers, daughter and son caregivers, other family member caregivers, and non-family member caregivers. Caregivers of demented individuals are a diverse group. Further understanding of help-seeking patterns by other groups of caregivers will illuminate commonalities and differences among the groups. This understanding will assist in discovering holistic practices and interventions that are specific to caregivers' needs.

Finally, a recommendation is made to shift from a view of service utilization to one of help-seeking. Through the viewpoint of help-seeking, lack of service utilization is viewed not as a problem to be fixed, but as an evolving pattern within the larger overall pattern of consciousness of caregivers. By interacting with the caregiver and assisting the caregiver with recognition of where they are in the pattern of transformation, the nurse can assist with the opening up of possibilities and choices.

Earlier pattern recognition will assist caregivers in making choices, one of which could be greater service utilization. Whatever choices the caregiver makes, the pattern will unfold. The nurse through being truly present with caregivers at choice points in their lives can assist in this process thereby helping both the caregiver and the care receiver.

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APPENDICES

Appendix A: Introduction to the Study

Introduction to the Study

You are invited to participate in a study which will explore wife caregivers' experiences, thoughts, and feelings about managing care and obtaining help in the care for their husbands with dementia. A goal of this study is to obtain information that will help health professionals to better provide assistance for wife caregivers to continue to provide care for their husbands.

You will be asked to participate in a 60 to 90 minute audiotaped interview in a place and at a time of your choice. You will be asked to share your experiences, thoughts, and feelings about managing care and obtaining help in caring for your husband. You may be contacted by the investigator after the interview to make sure she understood your comments and thoughts. At least 15 wife caregivers will be included in this study.

There is little risk to participating in this study. Some people may find it upsetting to discuss their problems and experiences. You may find it beneficial to discuss your experiences with the investigator. You are under no obligation to participate in this study, you can withdraw any time you want, and your decision will have no effect on any services that you are receiving or will receive in the future.

If you are interested in participating in this study, please sign the form giving this agency permission to release your name and telephone number to me. I will be telephoning you in two to four weeks to further explain the study and answer any questions that you may have. If you are still interested in participating after our telephone conversation, we will arrange an interview time that is convenient for you. If you should wish to speak to me before I telephone you, I can be reached at (423) 974-7621. If you choose to participate in this study, any information given will be treated in a confidential manner and your privacy will be protected in any presentations, publications, or reports of findings from the study.

I appreciate your taking the time to consider participating in this study.

Investigator:
Janet M. Witucki, RN, MSN
Doctoral Candidate
University of Tennessee, Knoxville
College of Nursing
(423) 974-7621

Co-investigator:
Martha Alligood, RN, PhD
Professor
University of Tennessee, Knoxville
College of Nursing
(423) 974-6804

Appendix B: Consent to Release Name/Telephone Number

Consent to Release Name/Telephone Number

I give permission to have Janet M. Witucki telephone me to further discuss the study described in the Introduction to the Study letter that was given to me today.

I understand that giving my permission to be contacted does not place me under any obligation to participate in the study explained in the letter.

I agree to have my name and telephone number released to Janet M. Witucki.

Name: _____

Telephone Number: _____

Agency: _____

Agency Person: _____

Appendix C: Demographic Questionnaire

Demographic Questionnaire

Please answer each question as completely as possible. If you do not feel comfortable answering any particular question(s), you can skip that question.

1. How old are you? _____
2. How long have you been married? _____.
3. What is the age of your husband ? _____
4. How many children do you have? _____
5. What are the ages of your children? #1 _____ #2 _____ #3 _____
#4 _____ #5 _____ #6 _____
6. Where do your children live? _____
7. How long has your husband had dementia? _____
8. Who told you that your husband has dementia? _____
- 8.. What type of dementia does your husband have?
 - a. Alzheimer's b. Multi-Infarct c. Parkinson's
 - d. Huntington's f. Pick's g. Other (specify)
 - h. Don't know
9. How long have you been responsible for the care of your husband? _____

Appendix D: Post Interview Questions

Post Interview Questions

1. Do you consider your income adequate to meet your needs?
2. How far did you go in school?
3. Have you sought any help in caring for your husband in the past month?
4. If so, where did you seek this help from?
5. Who do you usually call upon for help?

Appendix E: Study Consent Form

Help-Seeking by Older Wife Caregivers of Demented Husbands:
A Grounded Theory Approach
Consent Form

You are invited to participate in a research study involving wife caregivers of husbands with dementia. This study is designed to gain knowledge that will help nurses and other health professionals in the care of the elderly. The purpose of this study is to explore help-seeking by wife caregivers of husbands with dementia. As Principle Investigator in this study, I will ask you about your experiences, thoughts, and feelings associated with managing care for and obtaining help for managing care of your husband.

You will be asked to participate in a 60 to 90 minute audiotaped interview at a time and location of your choice. You will be asked to share your experiences, thoughts, and feelings regarding managing care and obtaining help in caring for your husband. Other questions will follow based on what you share with me. The interview will be audiotaped in order for me to use your exact words to compare with words of other women in the study. There will be at least 15 wife caregivers included in this study. All interviews will be typed into written form to allow for comparative analysis. Your name will not appear on the tape or the typed copy and will be known only to me. Information in the typed copies will be kept confidential. All copies, with no identifying information, will be kept in a locked file drawer in my home. I may contact you following the interview to make sure that I understood your comments and thoughts. The information obtained in this study may be put together with other information for future projects related to caregiving and elder health.

As a volunteer in this study, you will not be paid for your time and effort in participating in this study. However, a resource guide useful for caregivers of persons with dementia will be given to you after the interview. There is little risk for participating in this study. A few people may find that discussing difficult situations and experiences is upsetting. You may benefit from having someone to discuss your experiences with and from insights gained as a result of discussion. Information obtained from this study may help health professionals to better provide assistance for wife caregivers to continue to provide care for their husbands.

Participant's initials _____

You are free to answer or not answer any questions. You may choose not to participate or withdraw at any time during the study without any penalty or loss of present or future benefits to which you are otherwise entitled. Your audiotape will be destroyed if you withdraw from this study. Any information you provide will be kept in confidence. Your name will not be used in any reports although your words may be used to support interpretation and analysis. At no time will your words be identifiable with your name.

If you have questions at any time about the study or the procedures, you may contact the Principle Investigator or Co-investigator. Contact information appears below. If you have questions about your rights as a participant, contact the University of Tennessee, Knoxville, Compliance Section of the Office of Research at (423) 974-3466, or write them at 404 Andy Holt Tower, University of Tennessee, Knoxville, 37996.

Principal Investigator:

Janet M. Witucki, MSN, RN
Doctoral Candidate
University of Tennessee, Knoxville
College of Nursing
Phone: (423) 974-7621
Home phone: (423) 908-0588

Co-Investigator:

Martha Alligood, PhD, RN
Professor
University of Tennessee, Knoxville
College of Nursing
Phone: (423) 974-6804

I have read the above information and agree to participate in this study. I have had the study explained to me and I have been given an opportunity to ask questions. I understand that I may ask further questions at any time in the future by contacting the investigator. I can withdraw from this study at any time. I have received a copy of this consent form.

Participant's name (print) _____

Participant's signature _____

Date _____

Appendix F: IRB Approval Form

THE UNIVERSITY OF TENNESSEE
KNOXVILLE



03/12/99

Office of Research
404 Andy Holt Tower
Knoxville, Tennessee 37996-0140
PHONE: (423) 974-3466
FAX: (423) 974-2805
URL: <http://www.ra.utk.edu/ora>

IRB # : 5693 B

Title : Help-Seeking by Older Wife Caregivers of Demented Husbands - A
Gounded Theory Approach

Witucki, Janet Marie
Nursing
1458 Double D Drive
Sevierville, TN 37876

Alligood, Dr. Martha
Nursing
1200 Volunteer Blvd.
Campus

Your project listed above was reviewed. It qualified for expedited review and has been approved.

This approval is for a period ending one year from the date of this letter. Please make timely submission of renewal or prompt notification of project termination (see item #3 below).

Responsibilities of the investigator during the conduct of this project include the following:

1. To obtain prior approval from the Committee before instituting any changes in the project.
2. To retain signed consent forms from subjects for at least three years following completion of the project.
3. To submit a Form D to report changes in the project or to report termination at 12-month or less intervals.

The Committee wishes you every success in your research endeavor. This office will send you a renewal notice (Form R) on the anniversary of your approval date.

Sincerely,

A handwritten signature in cursive script that reads "Brenda Lawson".

Brenda Lawson
Compliances

cc: Joan Creasia

NOTE: The IRB discourages use of home telephone number on consent forms.

VITA

Janet Witucki was born in Stevens Point, Wisconsin on November 27, 1946. She graduated from Maria High School in Stevens Point in May of 1964. In 1967 she received a Diploma in Nursing from St. Joseph's Hospital School of Nursing in Marshfield Wisconsin. After working as a staff nurse on a Medical-Surgical Nursing unit at a local hospital, a staff coordinator and inservice director in a long-term care facility, and an Allied Health Instructor at a State Technical School, she enrolled in the Baccalaureate Nursing Program at Ball State University in Muncie, Indiana, receiving a Bachelor of Science in Nursing degree in 1991. While teaching at a State college and in the school of Nursing at Ball State University, she earned a Master's of Science degree in nursing from Ball State University in 1994. In August of 1996 she entered the University of Tennessee, Knoxville to pursue the Doctorate of Philosophy in Nursing. The doctoral degree was received May, 2000.

Presently, Janet is working as a nursing faculty member in the College of Nursing at the University of Tennessee, Knoxville. She is active in Alzheimer's and caregiving research, and serves on the Alzheimer's Memory Walk Planning Committee for Sevier County. She is also a volunteer parish nurse at Holy Family Church in Seymour, Tennessee and belongs to numerous professional organizations including the Southern Nursing Research Society, American Nurses' Association, and Sigma, Theta, Tau.