Management of Problematic Behaviors
by
Family Caregivers
for
Older Persons With Cognitive Impairment

by

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Most Sincerely,

Theresa A. Horvath

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Introduction

Recent decades have witnessed a dramatic increase in the mean life expectancy in the United states. One consequence of this extended longevity has been an increase in the number of older persons with chronic, cognitive impairments. Alzheimer's disease and other dementias are the major neuropsychiatric disorders affecting persons over the age of 65 (Barnes & Raskind, 1981). Although estimates vary, prevalance rates for dementias are thought to range from 4% (for severe impairments) to 20% (for milder forms) (Brody, 1982). One reason for the discrepancy in reported prevalance rates is that dementia (formerly called senile dementia or organic brain syndrome) has historically been a catch-all diagnosis--a poorly defined and frequently inappropriate label attached to older adults. Consequently, increased emphasis has been placed on the development of diagnostic criteria to determine the presence and degree of cognitive impairment in the elderly.

Although these criteria are an important part of the knowledge base related to chronic, cognitive impairments, more research is needed to identify the information which is essential for clinical decision-making in the nursing care of these individuals and their families. While the importance of cognitive aspects of aging has received increased recognition in the nursing literature, the focus has been on pathology and on nursing interventions based on medical diagnoses, rather than on nursing assessments and diagnoses (Burnside, 1980; Dietsche & Pollman, 1982; Palmer, 1983; Trockman, 1978). However, the clinical utility of nursing interventions based on what is known about a particular diagnosis, rather than on how that diagnosis is manifest in the individual or on the problems associated with the manifestation is questionable. Development of effective intervention strategies depends instead, on a comprehensive assessment of the relevant aspects of the clinical situation.

In defining the relevant aspects of the practice situation for older persons with cognitive impairment, nurses cannot ignore the significant ripple effect the impairment has on the individual's family. The burden of family care for older persons with cognitive impairment has been documented repeatedly in the literature. Several descriptive studies have identified the tremendous social, emotional, and economic strain of caring for older persons with cognitive impairment in the home (Fuller, Ward, Evans, Massan, & Gardner, 1979; Mann, 1985; Steuer & Clark, 1982). Other research has correlated caregiver feelings of burden with the common behavior problems related to the cognitive impairment (Zarit, Reever, & Bach-Peterson, 1980), and the social stigma attached to the presence of these behaviors (Goldman, 1982). The stress of caring for older persons with cognitive impairment is thought to be a major reason for nursing home placement of these individuals (Aaronson, 1982; Mann, 1985). In fact, the diagnosis of dementia accounts for greater than 50% of the institutionalized elderly population (Bergmann, Foster, Justice, & Matthews, 1978). Although this may be the result of inaccurate diagnoses of dementia, it may also reflect the inability of older persons with cognitive impairments to maintain independent, community living, and is suggestive of the heavy burden involved in the family care of these individuals.

Attempts at ameliorating the perceived burden of family care have focused primarily on changing the caregiver's perception of burden, rather than changing that which is burdensome. Some authors have identified coping mechanisms thought to be most effective in dealing with the emotional stress of caregiving (Pratt, Schmall, Wright, & Cleland, 1985). Others have promoted participation in caregiver support groups to allow therapeutic ventilation of feelings and frustrations associated with the provision of care (Barnes, Raskind, Scott, & Murphy, 1981; Fuller et al, 1979; Glosser & Wexler, 1985; Lazarus, Stafford, Cooper, Cohler & Dysken, 1981; Safford, 1980). Some literature has offered suggestions for interventions directed at the behavioral problems of the cognitively impaired. However, these articles are based largely on reality orientation and other behavioral modification techniques, the effectiveness and ethics of which remain controversial. Rather than working with the individual at whatever level he/she is capable, these strategies are aimed at improving functional status. Clinical observation of this approach suggests that not only are these methods futile in many circumstances, but they also engender false hopes for rehabilitation and frequently produce great amounts of anxiety and frustration for both the caregiver and the impaired older person. There is lay literature available which offers practical suggestions for the management and care of cognitively impaired older persons (Mace & Rabins, 1981). However, systematic investigation of the implementation of these strategies has not yet been performed.

Significance

Although the current extent and nature of family caregiving to older persons with cognitive impairment is largely unknown, several demographic changes have been predicted which will significantly impact family caregiving. The most notable change is the increase in the number and percentage of older persons by the turn of the century, particularly the increase in the "old-old", or those over 85 years (Committee on Aging, 1985). This older population is a group which is at increased risk for the development of chronic, cognitive impairments (Secretary's

Task Force on Alzheimer's Disease, 1984). At the same time when the demand for family caregiving is expected to increase dramatically, the decreased birth rate of that cohort will provide fewer available caregivers (Day, 1985). In addition, it is reasonable to assume that many of those persons "expected" to provide care to the old-old will be aged themselves and possibly experiencing some physical or cognitive disability.

Related to the trend of increased longevity is the high prevalence of frailty of those persons over 85 years (Committee on Aging, 1984). Advances in medical care have been primarily effective in preventing death from acute-onset illness and infections. Similar success cannot be claimed in the reduction of chronic illness. In fact, many of those individuals who might have died from complications of their chronic disease process are now able to survive and, consequently, are enduring many more years of disability than in the past. Although there is some evidence to suggest that persons with dementia may have a higher mortality rate, this has not been a consistent finding (Brody, 1982). Therefore, the requirements for care for these individuals might be of an extended duration.

The management of problems associated with family care of older persons with cognitive impairment is a growing concern in nursing. In fact, the National Institute of Mental Health made research in the area of cognitive impairments a national funding priority in 1985. In order for nursing to be more responsive to the needs of these families, a better understanding of the caregiving situation is needed. However, conceptualizations of the problems associated with the care of older persons with cognitive impairment currently offered by medicine, psychology, gerontology, and even nursing are insufficient to provide useful indications for the development of nursing intervention strategies appropriate to family caregiving. Consequently, the practice problem must be reframed to reflect more accurately the clinical reality of families caring for a cognitively impaired older person.

My own observations of clinical situations suggest that stress associated with family caregiving activities for older persons with cognitive impairment occurs primarily during the management of activities of daily living (ADL'S) and the behavioral problems associated with the cognitive impairment. In addition, analysis of qualitative data generated from clinical experiences suggests that some caregivers are particularly adept at recognizing and handling individual problematic behaviors or situations. However, the variables which significantly impact the caregiving situation have not yet been identified. Similarly, strategies which effectively address the problems which arise in caregiving have not, as yet, been articulated, although they may be intuitively accessible to caregivers.

This project presents the results of a qualitative study which attempted to identify more clearly those variables and strategies which seemed to facilitate family caregiving to older persons with chronic, cognitive impairment. The rationale for a qualitative approach relied on some assumptions about the use of grounded theory for nursing research and practice. A qualitative study attempts to identify the central variables of a given phenomenon in order to generate theory. Using the techniques of participant observation and intensive interviewing, massive amounts of empirical data are collected. The theory generated from the analysis of that data is called "grounded theory" (Glaser & Strauss, 1967) because it is "grounded in the empirical reality of the participants in the field" (Bunch, 1982, p.57). According to Dickoff, James, and Wiedenbach (1968), the first step towards the development of practice-based nursing theory involves "factor isolation", which is analagous to the identification of central variables. By explicating the phenomena of interest to nursing, one can develop conceptualizations which have practice relevance. Research questions which relate more directly to practice should then emerge from the conceptualizations. Grounded theory methodology has the potential to lay important groundwork for future development and testing of nursing theory. By framing the problems of and strategies for caring for cognitively impaired older persons with theory grounded in the empirical reality of the caregiving situation, it is hoped that nursing can become more responsive to the needs of families caring for cognitively impaired older persons.

Review of Literature

In conducting a review of literature prior to beginning a qualitative study, the researcher must be concerned with the development of biases through the discovery of concepts identified in the literature. However, this possible "contamination" must be balanced with an adequate understanding of the prevailing knowledge base in order to justify further research in the area. For purposes of clarity, the review of literature which preceded this investigation is divided into three sections. The first section examines more closely current conceptualizations of cognitive impairment in the nursing literature by exploring how the problem is identified, what assessment techniques are employed, and which intervention strategies are recommended. The next section focuses on the general caregiver literature and its applicability to the current topic. Finally, a review of the caregiver literature specific to families caring for an older person with cognitive impairment is presented. This review of literature demonstrates how current understanding of the clinical problems facing families caring for an older person with a cognitive impairment are inadequate to direct nursing care for these families.

Cognitive Impairments. The literature published in nursing journals focusing on cognitive impairment is generally written about Alzheimer's Disease. Unfortunately, there is very little scientific research in nursing in this area. In several descriptive articles, the authors characterize the problem as a "change in mental status" (Hirschfeld, 1976), or "cognitive disruption" (Palmer, 1983). However, there are no criteria cited to support these assertions.

A few authors suggest the use of tools to assist with assessment, yet the basis for development of the instruments is not disclosed, nor is there any reporting of reliability or validity information (Adams, Hanson, Norkool, Beaulieu, Bellville, & Morss, 1978; Chisholm, Denniston, Igresen, & Barbus, 1982; Ludwick, 1981). Whereas some authors omit assessments completely by going directly from medical diagnosis to intervention (Burnside, 1980; Hirschfeld, 1976; Trockman, 1978), others suggest that assessments are useful to substantiate the diagnosis and should be based on knowledge of the disease process (Charles, Truesdell, & Wood, 1982; Dietsche & Pollman, 1982; Palmer, 1983). Bartol (1983) does begin to move out of the diagnostic-related model through identification of cognitive capacities which are impaired without compensation. It is not known, however, how these impairments relate to the functional aspects of the caregiving situation of the impaired older person.

Wolanin and Phillips (1981) have been instrumental in developing a more comprehensive approach to cognitive assessment through their concept of "holistic assessment". Their work, based on qualitative research, suggests that confusion is the behavioral manifestation of impaired cognitive processes. While acknowledging that the impairments are influenced by pathology, their assessment tool focuses on functional abilities. Their model does not, however, include environmental or interactional variables of the caregiving situation. The tool they have developed has not yet been subjected to experimental testing, but the approach is an important redirection of the conceptualization of cognitive impairments.

It becomes apparent from this review, that the development of the knowledge base related to the nursing care of families caring for a cognitively impaired older person is still embryonic. Further work is necessary in order to conceptualize the problems in a way that effectively directs the development of nursing interventions.

Caregiving: General. Informal family caregiving is considered by many to be the linchpin in the delivery of long-term care in the United States today (Reif & Estes, 1982). Shanas (1960, 1979) documented the presence and extent of family care of older adults. Despite this evidence, however, the popular myth of family alienation and abandonment of older persons continues.

In fact, only about 5% of those persons over 65 years currently reside in nursing homes (Committee on Aging, 1985). Several authors have even identified that the presence of a family caregiver is a critical variable in delaying nursing home placement (Brody, Poulshock, & Masciocci, 1978; Shanas, 1978). Still, older persons with a diagnosis of dementia continue to be overrepresented in the institutionalized population (Bergmann et al, 1978; Eisdorfer & Epstein, 1977). This may be the result of a misdiagnosis of dementia, but is also suggestive that this is either a particularly stressful caregiving situation, or that individuals with physical impairments are better able to maintain an independent living situation than those with cognitive impairments. The advent of diagnostic-related groups (DRG's) may, of course, change the size and make-up of the institutionalized population. Although more recent national probability data are not yet available, predicted shortages of skilled nursing care beds combined with heavier care demands may result in an even larger burden of care for the families of impaired older persons (Brody, Lawton, & Liebowitz, 1984).

In addressing the long-term care needs of the elderly, an understanding of the nature of the caregiving situation is important. In a pivotal study by Archbold (1982) two types of caregiving roles were identified. Up until that time, researchers spoke of only one caregiving role. Using qualitative methodology, Archbold found that, based on socioeconomic status, housing arrangements, onset of illness, and past experience with caregiving, women caregivers adopted either a care manager or a care provider role. The problems in caregiving and the cost to the caregiver differ significantly with the assumption of the different roles. No research has yet been conducted to determine whether the development of a chronic cognitive impairment might influence which caregiving role is assumed.

Caregiver strain has been studied by several authors. Although some research has shown that different types of caregiving situations are associated with different types and degrees of strain, most researchers fail to differentiate between the situations in their sampling and/or analysis techniques. Worcester and Quayhagen (1983) used proxy measures in their study of caregiver strain. They asserted that characteristics of the impaired older person influence caregiver satisfaction which is then predictive of nursing home placement. In an ex post facto correlational study, they compared 19 current caregivers with 29 past caregivers on measures of current situational stress. They found that past caregivers had higher levels of reported environmental stress ($t=5.38$, $p<.001$) and situational stress ($t = 3.19$, $p <.01$) than current caregivers. These differences in stress were attributed to differences in caregiver strain and were thought to account for nursing home placement. Their framework assumes that nursing home placement is a result of caregiver strain, and that caregiver strain results in nursing home placement-- assumptions not entirely supported in the literature.

Reporting on data drawn from a larger study, Cantor (1983) suggested that situational, demographic and attitudinal variables influence a caregiver's response to the caregiving situation. However, the situational variables she describes do not include differences in the impaired older person's functional status. Instead, they relate to factors such as proximity to the impaired older person, and the work and health status of the caregiver. From interviews with 111 caregivers served by a major homemaker service, she found that the quality of the caregiver-impaired older person relationship, the amount of care, and the amount of lifestyle change required by the caregiving situation, significantly influenced the perception of caregiver strain. Her analysis did not, however, include an examination of the specific care requirements of the impaired older person which were perceived to be burdensome.

More recent research by Montgomery, Gonyea, and Hooyman (1985) identified that within the caregiver role, two different kinds of burden exist--subjective and objective. Subjective burden referred to the feelings, attitudes and emotions associated with caregiving and was measured using a 13-item, 5-point inventory adapted from Zarit et al's (1980) 29-item instrument. Objective burden related to the events, happenings, and activities of the caregiver role and was measured with a 9-item, 5-point scale asking respondents to rate the extent to which caregiving influenced nine areas of their lives (e.g., amount of privacy, time, personal freedom). Using ex post facto correlational design (n=80), the relationship between caregiving behavior and the differential experience of burden was examined. Caregiving behavior was measured with a list of 21 caregiving tasks. Subjects were asked to report the number of hours per week they spent performing each task. These researchers found that the functional level of the impaired older person, as it influences the type of caregiving tasks, was an important variable in the conceptualization and measurement of burden. They did not draw a distinction between functional impairment related to physical or cognitive disability, nor did they measure caregiver tasks specific to the care of cognitively impaired older persons.

Although conceptualization of caregiver burden and strain may be similar for all caregiving situations, the differences in the care needs of older persons with cognitive versus physical impairments warrant separate investigation into the issue of strain and those strategies which are effective in reducing the strain. It is evident from reviewing the general caregiver literature that the investigation of caregiver strain has not made a clear distinction between these different caregiving situations.

Caregiving for Cognitively Impaired. The situation for families caring for older persons with cognitive impairment has been described in several different ways. Teusink and Mahler (1984) compared the family's reaction to the diagnosis of Alzheimer's Disease to Kubler-Ross' stages of grief. This comparison does not, however, offer suggestions for managing the problems which arise during caregiving. Some authors (Hayter, 1982; Gwyther & Matteson, 1983) prescribe nursing interventions for families of Alzheimer's patients based on the stage of the illness. However, the literature remains divided on what the stages of the disease are, and whether staging is an appropriate way of thinking about the disease and its progression. In the qualitative study by Hirschfeld (1979) noted earlier, the author explored the factors which influence continued family caregiving for older persons with dementia. Through in-depth, focused interviews with 30 caregivers, she identified that mutuality between the impaired older person and the caregiver was an important variable in the decision to consider nursing home placement. Other variables included the management ability and morale of the caregiver. She also identified the need for further research in this area to understand more fully, this complex caregiving situation.

In a classic study of family caregiving for older persons with cognitive impairment, Zarit et al. (1980) examined the effects of problematic behaviors, which were related to cognitive impairment, on caregiver feelings of burden. This descriptive study involved interviews with the primary caregivers (n=29) for older persons with cognitive impairment where burden was measured with a 29-item self-report inventory. The caregiver also filled out a checklist of "common memory and behavior problems". In addition, the cognitive status of the older person was measured with the Mental Status Questionnaire and the Face-Hand Test, and functional impairment was determined with the Lawton Physical and Instrumental ADL Scale. The measure of perceived burden was then correlated with the levels of cognitive and functional impairment for each caregiving dyad.

The results showed no correlation between burden and the behavioral, cognitive, or functional variables. There was a significant negative correlation between burden and the frequency of family visits (r=-.48, p<.01). The surprising findings of this study might be explained by methodological weaknesses (lack of random sample, low overall measurement of burden, or other measurement problems). It also suggests that viewing the presence of caregiver strain from a cause and effect framework might be an oversimplification of the situation, and be masking important intervening or mediating variables.

A recent study (Pratt et al, 1985) examined perceived caregiver burden and the presence of effective coping strategies. They hypothesized that the presence of inter- and intrapersonal resources would correlate with a decreased perception of burden. Using the Caregiver Burden Scale developed by Zarit (α reliability= .79) and the F-Copes to measure coping strategies, 240 caregivers, accessed through local chapters of the Alzheimer's Disease and Related Disorders Association (ADRDA) were interviewed. Analysis of the results revealed that burden scores were not significantly correlated with the presence of social support, but did relate to caregiver health status. An interesting finding was that even with the transfer of the impaired older person to a nursing home, a high degree of burden persisted. This is inconsistent with the popularly held belief that nursing home placement will decrease the stress of caregiving. This might be explained by a continuation of care management responsibilities which may be burdensome, or may be a reflection on the sensitivity of the burden instrument. In addition, Montgomery et al. (1985) suggest that <u>subjective</u> burden (which that tool measures) is not related to the nature of the caregiver's role, but to characteristics of the caregiver. The researchers also found that some coping strategies were significantly correlated with lower levels of burden. The coping strategies which were correlated with lower levels of burden were confidence in problem-solving ($r=-.18$, $p<.01$) and reframing ($r=-.15$, $p<.05$). Although the statistical significance of these findings may be related to the large sample size, they do suggest that it is possible to reduce not only the caregiver's perception of burden through reframing, but also the actual burden of caregiving through effective problem-solving.

Finally, a number of researchers have explored the caregiving situation through the use of caregiver support groups. The support groups would generally focus on educating the caregiver (Lazarus et al, 1981), providing emotional support (Barnes et al, 1981), or be a combination of both (Glosser & Wexler, 1985; Safford, 1980). The variation in focus of the groups and the differential strategies for analyzing their effect has created a paucity of comparable data (Steuer & Clark, 1982). Still, some conclusions can be drawn from these studies. First, some caregivers report a dramatic reduction in burden as a result of participation in the group; others have not found it at all helpful. The characteristics which distinguish between these two groups are not known. Second, part of the relief that is reported is attributed to a reduction in the perception of burden. Sharing a similarly difficult situation seems to provide comfort to certain caregivers. Finally, all of the authors report that the practical sharing of information and strategies between caregivers is an invaluable aspect of the group. To date, no one has systematically analyzed the content of that information. It seems reasonable to hypothesize that the reported decrease of burden associated with participation in support groups might be a combination of decreased perceived burden (through emotional support) and a decrease in actual burden (through sharing of practical caregiving strategies).

This review of literature reveals that deficits currently exist in the nursing knowledge base for family care of older persons with cognitive impairment. Conceptualizations with a diagnostic focus fail to capture the phenomena of interest in nursing care of these families. In fact, those variables of the caregiving situation which would influence the development of nursing intervention strategies have not, as yet, been identified in the literature. This lack of a clear conceptualization of the phenomena central to family caregiving for older persons with cognitive impairment prompted the current study.

Chapter II

Methodology

Sample

In this study, purposive sampling was used to identify family caregivers for older persons with cognitive impairment. The sample consisted of six family caregivers for six older persons with cognitive impairment from five caregiving situations (one caregiver took care of two older persons, and one older person was cared for by both his wife and daughter). Three of the caregivers were caring for their husbands, one for her mother, and one woman was taking care of her son's in-laws. The caregivers were all female and ranged in age from 42 to 75; three were married, two were widowed, and one was single. This sample was drawn from two sources--an outpatient clinic of a general hospital and a community service agency, both located in a major metropolitan area in the Northwest--where a nurse clinician and the field workers were asked to identify families who were caring for an older person "with memory problems". Inclusion was based on the presence of a caregiving situation, while the criteria for cognitive impairment remained loosely defined. This was done to include older persons with cognitive impairment related to multiple diagnostic categories in order to avoid the pitfall of prematurely linking nursing theory to specific diagnoses.

Data Collection

The data were collected during unstructured interviews with the caregiver and, when possible, through observations of the interaction between the caregiver and the older person with cognitive impairment. The interviews, each of which lasted from 1-2 hours, consisted of questions about the caregiving situation, the problems encountered, and the strategies used to manage the problems (see Appendix A for sample questions). Written notes were taken on all the answers during the interview and afterwards, type-written fieldnotes were generated. All of the caregivers were interviewed once except for the woman caring for her son's in-laws. She was interviewed twice because of her particular effectiveness in caregiving and the insight she was able to articulate so clearly.

Due to the nature of the questions, all but one of the interviews were conducted in a room separate from the older person with cognitive impairment. This was to allow a more complete and uninhibited discussion of the problems encountered by the caregiver and to avoid the awkward situation of discussing the older person in his/her presence. The one exception occurred when a caregiver insisted that her husband would "feel left out" if he were not included in the interview. The format of that interview was altered slightly to accomodate the husband's presence. Instead of asking the caregiver about the problems which arose during caregiving, they were both asked about some of the changes which have occurred since she began taking care of him, and how they managed some of problems which are commonly associated with a stroke (i.e., immobility, weakness, speech and memory impairment). Although this type of interview arrangement did not permit a focused discussion of the management of problems related to the cognitive impairment per se, it did provide an opportunity to observe, more closely, the interaction and communication pattern between the caregiver and the older person, and their interaction with a third party.

The decision to discontinue data collection when conducting qualitative research is generally made when the research reaches a point of "saturation" (Glaser & Strauss, 1967). Saturation occurs when no additional data are collected which contribute to the further development and refinement of the emerging theory. Although a point of theoretical saturation has not yet been reached in this study, data collection was discontinued for three reasons. First, the collection and analysis of data progressed to a point where a more focused and structured interview technique is needed. Second, it is planned that the next step of more focused data collection and analysis will involve different analytic techniques in order to broaden the author's experience in qualitative research methods. Third, this study is only the first step in a planned program of continued research and a precursor to a doctoral dissertation.

Record-keeping

The massive amount of data generated from the interviews demanded an organized approach to record-keeping. The "raw data" from interviews and observations were recorded after each visit as fieldnotes. The fieldnotes were organized using Schatzman and Strauss' (1973) scheme of observational, theoretical, and methodological notes. Typing of the notes was done on a word processor so that two sets of records (floppy disc and printed page) could be maintained to insure against loss or damage. An additional advantage of the word processor was easy manufacture of several copies of the fieldnotes for the cut and pasting of the analysis phase. In addition to the fieldnotes, a log was kept of the visits, noting name, address, and phone number of the family, and the date and time of the visits.

An integral part of any record-keeping system in qualitative research is the ongoing record of theory development. This study utilized a combination of methods whereby data in the fieldnotes were coded in the left margin and a listing of the coding categories were recorded separately on note cards. The properties which define each of the categories were recorded on the file cards, along with an illustrative quote from the raw data when appropriate. All entries, updates, and changes in the categories were dated so that the development of the emerging theory could be traced.

Due to the comprehensive and sometimes sensitive nature of the information contained in the fieldnotes, identifying information was excluded from them. To further protect the confidentiality of the information shared during the interviews, the log containing specific identifying information was kept separate from the fieldnotes.

Data Analysis

For this study the data were analyzed using a process of theoretical coding with constant comparative analysis (Glaser & Strauss, 1967). Data analysis, which occurred simultaneously with, and in fact, directed data collection, progressed through four different, yet overlapping phases. First, after the observational notes for each interview were typed, theoretical and methodological notes were generated. The theoretical notes were typewritten discussions and interpretations of the general ideas and themes which seemed to be reflected in the observational notes. The methodological notes contained commentaries on the interview procedures and plans for further data collection.

Next, the observational notes were reviewed and significant pieces of data were underlined. Data were recognized as significant if, for example, they described a problem or intervention, or represented an idea or theme repeated in the notes. One- or two-word descriptions of the underlined data were then recorded in the margins. These descriptions formed the beginning of the coding categories used to develop the final conceptualizations. Although this second phase of data analysis was predominantly an intra-interview analysis--identifying the key elements for the individual caregiver's mode of operation--the analysis of each successive interview drew on the theoretical notions from the previous ones in the process of identifying important elements to be coded.

The third phase of data analysis involved more emphasis on inter-interview similarities and differences. During this phase of analysis the coding categories from the margins of each interview were collected and recorded on note cards, along with a description of the properties which seemed to define these categories. Additional passes through the fieldnotes were made to look for data in one interview which could be coded or recoded based on evidence from another. This cross-validation of coding categories with empirical data was performed in an effort to prevent the development of conceptualizations based on behavior idiosyncratic to a single caregiver.

Upon completion of data collection, a final, more intensive phase of data analysis ensued. During this fourth phase of data analysis, the previously identified coding categories were synthesized to form a list of concepts thought to be central to the situation of families caring for an older person with cognitive impairment. This list of concepts and the fieldnotes from two interviews were then submitted to the committee overseeing this research for their assessment of the fit between the concepts and the raw data. A conference with the committee produced a preliminary conceptual model, identifying hypothesized relationships between concepts and new areas of literature to be reviewed for their relevance to the emerging theory.

After reviewing additional literature and revising the model, the data were reviewed again to refine further the model--checking and cross-checking for instances where the model did not describe or explain the empirical findings, making adjustments in the framework to accomodate those instances, and rechecking the revised model with the data. Finally, after this systematic effort to pinpoint, refine and reduce the data into theortical categories, the current conceptual framework for the processes and strategies involved in managing the problems associated with cognitive impairment was produced. Before the conceptual framework can be presented, however, it is important to address some of the design issues which have influenced the results of this study.

Design Issues

The issue of validity in qualitative research is controversial. Whereas some researchers maintain that qualitative research is inherently valid because it is derived from empirical data (McCall & Simmons, 1969), others argue that threats to validity can and must be consciously controlled or built into the study (Taylor & Bogdan, 1984). Still others suggest that validity in qualitative research is conceptually distinct from quantitative research and, consequently, must be estimated using separate techniques and criteria (Sandelowski, 1986; Stern, 1985). For this study, threats to internal validity, as described by Polit and Hungler (1983), were treated as data and included in the analyses. For example, it was noted earlier that purposive sampling was used to identify family caregiving situations for older persons with cognitive impairment. Although this non-random selection of subjects may have resulted in a biased, unrepresentative sample, the unique characteristics of each subject were recorded and used to weigh and analyze data.

Another sampling issue germane to validity issues in qualitative research is "theoretical sampling". According to Glaser and Strauss (1967), theoretical sampling is "the process of data collection for generating theory whereby the analyst (researcher) jointly collects, codes and analyzes his data and decides what data to collect next...in order to develop theory as it emerges" (p.45). The basic question in theoretical sampling is "where do I go next in search of new data?" The adequacy of theoretical sampling is determined through estimates of construct and content validity. During the data collection and analysis procedures for this study, the initial observations and analyses were taken back to a key informant to check the accuracy of the observations and conceptualizations. She concurred that "the main things were pulled out". In addition to checking with a key informant, a list of the concepts identified as central to family caregiving for older persons with cognitive impairment, along with the fieldnotes from two interviews, were given to the committee overseeing this research. Each committee member reviewed the data and the categories, and discussed agreement and/or disagreement with the investigator's coding. This was done to insure that the emerging conceptualizations were developing in a direction consistent with the data, and from a perspective relevant to clinical practice.

In addition to the procedures used for this MRP, efforts at estimating construct and content validity will continue throughout subsequent phases of this planned program of research. During this next, more focused phase of research, several methods for estimating validity will be employed. First, a list of the coding categories which link the concepts to empirical data will be submitted to a panel of experts in the fields of qualitative research, family caregiving, and mental health nursing. They will be asked to determine the adequacy of the "fit" between the data and the categories, or whether any gaps or ambiguities in coding exist. In addition, the panel will be asked to evaluate the clinical relevance of the concepts and their hypothesized relationships, and the extent to which this conceptual framework addresses the problems associated with family care of older persons with cognitive impairment. It is hoped that by attending to issues of construct and content validity throughout this program of research, the nursing intervention strategies which are finally derived will have utility for clinical practice.

Closely related to issues of validity is the concept of bias. Biases are the preconceived conceptualizations and beliefs about a phenomenon or situation which distort or prejudice the development of grounded theory from empirical data. Bias can significantly influence theory development in qualitative research. Rather than basing theory on empirical data, the biased researcher is at risk for reporting what he/she thought was "supposed" to happen (McCall & Simmon, 1969). In other words, the theory is not grounded in the empirical reality of the clinical situation, but in the contrived reality of the researcher's biases. Adequately dealing with bias is an important part of the research process.

For this study, the biases which came from preconceived notions of family caregiving to older persons with cognitive impairment were handled in several ways. First, prior to beginning the unstructured interviews, essays were written describing the researcher's ideas regarding cognitive impairment and family caregiving. By identifying assumptions and hypotheses a priori, a more thorough examination of how the biases might be influencing data collection and analysis was possible. Continued exploration of self for developing or persistent biases also occurred in the methodological and theoretical notes. By examining how the new data were or were not consistent with long held ideas about older persons with cognitive impairment, it is hoped that the distorting effects of bias were held to a minimum. In addition, the processes of construct validation will facilitate bias identification and promote empirical grounding of the conceptualizations.

Chapter III

Results and Discussion

The analysis of data from unstructured interviews with family caregivers for older persons with cognitive impairment suggests that those situations where individual problematic behaviors were managed successfully differed from those which were managed with less success in important ways. Those differences involved the process by which the caregiver: (a) perceived the older person's behavior, (b) attributed causality and/or meaning to the behavior, (c) evaluated the behavior as problematic, (d) evaluated the problem as amenable to change, (e) developed and implemented an intervention strategy, and (f) evaluated the efficacy of the intervention (see Figure 1). In situations where the caregiver was successful in her* approach to managing a problematic behavior, the process reflected an integrated understanding of the older person's cognitive impairment. In contrast, in situations where the caregiver was less successful, her description and evaluation of the behavior reflected little insight into the older person's cognitive impairment, or, this insight was not integrated into the development and implementation of the interventions.

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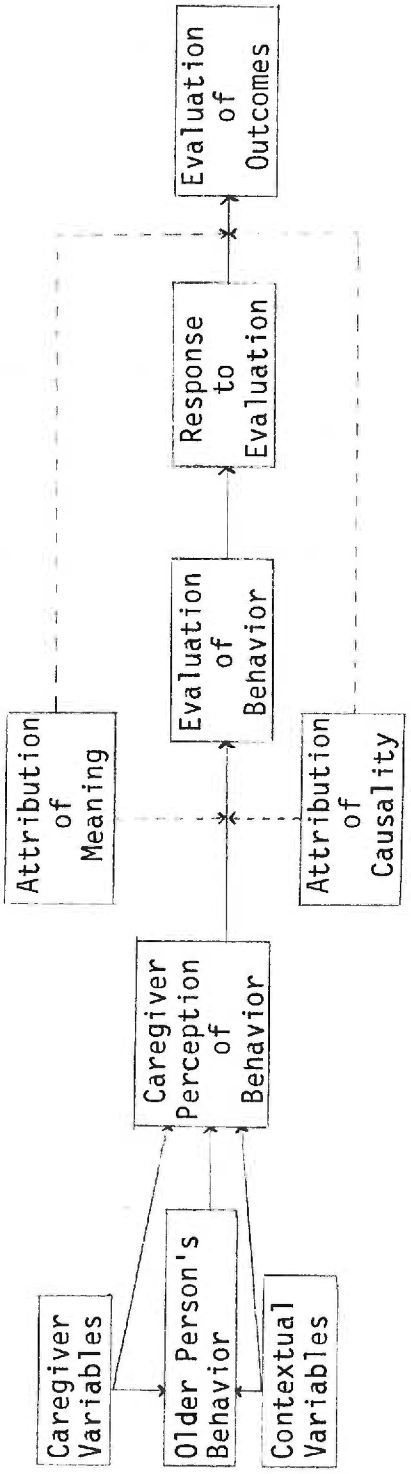
*The feminine pronoun will be used throughout this discussion to refer generically to caregivers.

Figure 1: Process for Managing Problematic Behaviors



----- denotes mediating or indirect influence

Additional evidence suggests that a number of variables influence the caregiver's process of perceiving, evaluating, and managing the older person's behavior. Some of these are antecedant to the caregiver's perception (e.g., contextual variables associated with each behavior), while others are variables which generally characterize the caregiver (e.g., her philosophy of care, her assessment of the older person's cognitive functioning, and her perception of her relationship with the older person). While it is not within the scope of this Master's Research Project (MRP) to delineate specifically the antecedant variables and characteristics of the caregiver which impact the caregiver's perception, evaluation, and management of the older person's behavior, general recognition of their influence is important.

Another interesting finding suggests that caregivers who tend to perceive and evaluate the older person's behavior in terms of the underlying cognitive impairment have a larger repertoire of strategies from which to choose when managing problematic behavior. Caregivers who are less successful not only fail to associate consistently the problematic behavior with the cognitive impairment, but they also seem to have fewer number of available strategies. It is as though an uninformed view of the factors contributing to certain problematic behaviors is associated with a limited number of intervention strategies, while a more insightful perspective is accompanied by a larger repetoire. This may reflect a developmental process that some caregivers experience during the course of caring for an older person with cognitive impairment.

Definitions of Process Variables

In this section, the theoretical definitions of the variables central to the process of managing individual problematic behaviors are outlined, and the hypothesized relationships between the variables are discussed. Some examples from the data which typify the concepts are also presented for illustration.

Caregiver perception of the behavior. This refers to the caregiver's recognition and description of the older person's behavior or lack of behavior for any given situation. It is her description of what is happening that should not be happening, or what is not happening that should be happening. This recognition and description of the older person's behavior is influenced by characteristics of the caregiver, and the context within which the behavior occurs.

> Sometimes (when we go shopping) he will wander--he has forgotton to watch me. I used to be able to handle it because I knew the Fred Meyer store like the back of my hand. Now they have that new store and I have to

> watch the signs and the aisles and him all at the same time and it is difficult.

The words used to describe the caregiver's awareness of the behavior reflect the aspects of the behavior on which she chooses to focus. This focus then sets the stage for whether or not the behavior is perceived as problematic (see Figure 2).

Figure 2

Perception of Behavior -------> Evaluation of Behavior

Problematic

Not Problematic

Attribution of causality. This refers to the caregiver's conceptualization of the underlying causes or conditions which give rise to the older person's behavior. An important aspect of the caregiver's explanation of the cause of the behavior is whether or not it reflects an understanding of the older person's cognitive impairment. Some caregivers provide a very elaborate explanation for the older person's behavior:

> He hasn't forgotten, some of his brain is gone. The audio nerve doesn't transmit the right message. The visual nerve doesn't transmit the correct image. It has something to do with the way the brain is damaged with the Alzheimer's

The attribution of causality seems to also involve several different, yet related, factors. The first pertains to the caregiver's perception of whether or not the behavior is deliberately directed at herself. It seems that behavior seen as a result of the cognitive impairment is perceived as less intentionally directed:

> He just doesn't know how to feed himself. He takes the first bite and then doesn't remember how to continue, then we have to feed him.

In contrast, behavior not attributed to the cognitive impairment is viewed as having a greater element of intentionality. Behavior which the caregiver perceives as directed at self seems to cause tension between the caregiver and the older person:

> The other day she just couldn't hear what I was saying so I said "let me test your (hearing aid)

> batteries". And she said "they're just fine". She won't let them be tested--it's as if her last penny depended on buying those batteries. Finally she let me have them and they were dead as a door nail. I put new ones in and gave them back to her and said "now see if that isn't better." She said "I'm going to take a nap so I don't need to put them in." She was clever enough to know she doesn't wear them when she lays down. She won't give in and give me the satisfaction...

The attribution of causality also seems to be linked to the caregiver's emotional reaction to the older person's behavior, thus influencing her evaluation of the behavior. Failure to attribute the behavior to the cognitive impairment seems to be associated with the presence of negative feelings and emotions:

> Another thing she does is she thinks all the time that when we go driving I am lost. You see, when we first moved here I would get lost frequently and end up at the zoo...Well, now I know my way around pretty good, but she always thinks we are lost and she will pester me to pull into a gas station to ask for directions...I get angry and tell her I know the way, but she just keeps asking "are we lost?"

On the other hand, an understanding that the behavior is influenced by the older person's cognitive impairment seems to be associated with milder emotional reactions:

> He's not as talkative as he used to be. Several years ago I blamed him alot till I realized the degree of the problems, then I changed my attitude.

What is not clear from these data is whether attributing causality to the cognitive impairment acts to buffer the emotional reaction to the behavior, or, if it is the caregiver's emotional reaction to the behavior which does or does not allow her to attribute causality to the cognitive impairment.

Finally, the attribution of causality for an older person's behavior seems to be related to the caregiver's acceptance of the impairment. The ability to attribute the behavior to cognitive impairment seems to be related to the extent to which a caregiver indicates an increased acceptance of the cognitive impairment:

> You have to get to the point where things don't shock you. The things you take for granted can be frightening; you have to realize that that's the way the disease is.

Despite the lack of clarity regarding the dimensions of the attribution of causality, it does seem to mediate the caregiver's evaluation of whether the behavior is problematic (see Figure 3). Although the exact nature of the relationship between the attribution of causality and the evaluation of the behavior is not clear from the data, several hypotheses are suggested. It may be that with increased acceptance of the cognitive impairment, the caregiver is able to attribute the cause of certain behaviors to the cognitive impairment, thus influencing her evaluation of the behavior as less problematic. Similarly, behavior viewed as being unintentional or not directed at the caregiver may be less of a problem than behavior which the caregiver perceives to be directed at herself. In addition, behaviors which evoke more powerful emotional reactions may be seen as more problematic than those which arouse very little. Clearly, further investigation is needed to understand this complex process.

Figure 3

Attribution of Causality =======> Evaluation of Behavior

Not Problematic

Problematic

===> denotes indirect or mediating influence

Interestingly, the nature of the caregiver's explanation of causality for the older person's behavior can be a double-edged sword. While attributing causality to the cognitive impairment may soften the caregiver's emotional reaction to the older person's behavior, it may also reduce the perception that anything can be done to change the behavior (see Figure 4).

Consequently, the attribution of causality of the older person's behavior, as it reflects the caregiver's understanding (or lack thereof) of the older person's cognitive impairment, indirectly affects her evaluation of the behavior by mediating the caregiver's perception of the behavior. This can be seen in both the determination of whether the behavior is a problem, and whether it is amenable to change.

Figure 4

Attribution of Causality =======> Evaluation of Behavior

Not Amenable to Change

Amenable to Change

===> denotes indirect or mediating influence

Attribution of meaning. The attribution of meaning is the process whereby the caregiver takes her explanation of the cause of a given behavior to a higher level of abstraction in order to reframe the older person's behavior in a more positive light. This again mediates the caregiver's perception of the behavior, influencing her evaluation of the behavior as problematic or not.

> She is on a water binge lately. I think it's a holdover from living in Kansas where it was always so dry. She waters all of her favorites (plants) six times and leaves the others to go dry. I have to go back and undo some of what she has done or else they would die if they stayed in that much water. But, I figure the exercise is good for her and so I just let her do it.

> He was always busy with his hands. Then, when he got Alzheimer's he still tried to keep busy. He'll take the newspaper and rub the table with it. I think he is sanding it.

The ability to attribute meaning to a behavior appears to increase the personal significance of the behavior, thus making it seem like less of a problem, or no problem at all.

Evaluation of the behavior. This refers to the caregiver's appraisal of her perception of the older person's behavior. Evaluation of the behavior includes first, a determination of the extent to which the behavior is problematic. It was noted earlier that attribution of meaning to the older person's behavior frequently results in a determination that the behavior is not a problem or is a tolerable problem. If, however, the caregiver is unable to attribute meaning to the behavior, it is usually identified as a problem:

> She always likes to go, but as soon as we get somewhere she wants to go home...We went out for lunch with my brother's mother-in-law...After we ate lunch, she began to stack the dishes and clean her plate with her napkin. I was so embarrassed. L. said "just let her do it", but there were people kind of looking at us.
>
> She loves to bring in the mail. She will check the mail three and four times a day and after she brings it in she will check it again. I have thought that it isn't too bad, but then I found the Visa bill in her dresser and thought maybe that will be a problem.

After defining a behavior as problematic, the caregiver then decides whether it is amenable to change. Conflict can arise when the caregiver's perception of the behavior as amenable to change does not reflect an adequate understanding of the older person's cognitive impairment:

> I used to say to her "now concentrate, you just asked me that. What is the answer? You know!". I think sometimes people need to jack themselves up when they are having problems.

Based on her evaluation of whether the behavior is amenable to change, the caregiver decides how to manage the problem situation.

Response to the evaluation of the behavior. A caregiver's response to her evaluation of a behavior is her decision on whether and how to manage the problem situation. Management of the problem situation may involve attempts by the caregiver to change or stop the problematic behavior or efforts at controlling the sequelae of the behavior. It may also result in a decision not to act at all, although she may continue to monitor the older person to determine if action will be required in the future (see Figure 5). If the caregiver perceives that a problematic behavior is not amenable to change, she may not intervene to try to change the behavior, although she may act to control the side effects of the behavior:

> He doesn't always remember about his pills and sometimes he forgets that he has asked me about them. So I set out his pills the night before so he knows what to take and so he doesn't miss a dose or double dose. Then he can see that he took the pills.

Problematic behaviors which are perceived as amenable to change may precipitate attempts by the caregiver to intervene to change or arrest the behavior:

> He gets mixed up dressing, so I lay out his clothes... I direct him. He'll ask "which one?" and I'll guide him a little and tell him what to do. I try to keep him resourceful. I get him to do as much as he can.

> Last summer he ran away all the time so we had to be with him all of the time. We would go for walks when he started to get restless. We would try to keep him occupied in the evening so he couldn't walk off.

Figure 5

Evaluation of Behavior		Response to Evaluation
Problem: amenable to change	------>	Intervention to change behavior
Problem: not amenable to change	------>	Intervention to control sequelae
Not a problem	------>	No action/vigilance

An important aspect of the caregiver's development and implementation of interventions used to manage problematic situations (i.e., the problematic behaviors and the fallout from the behavior) is the extent to which those strategies reflect an _integrated_ understanding of the older person's cognitive impairment. Part of this integration may be the caregiver's acceptance of the impairing condition. In some situations, it is evident that the caregiver has incorporated her understanding of the older person's cognitive impairment into her actions. One caregiver described the way she handled her husband's wandering by installing new locks which required coordinating a sequence of maneuvers in order to unlock the door. Because of his cognitive impairment, he was unable to figure out and remember the sequence. Consequently, he was unable to wander in the middle of the night.

In other situations, the development and implementation of a plan for management are inconsistent with the caregiver's attribution of causality which had reflected, initially, an understanding of the older person's cognitive impairment:

> She shadows me because she's insecure. I read 36-Hour Day and now I realize that she can't help it so that helps...But the other day I was doing monthly bills and she kept interupting me...Finally I just said "I can't do this with you here. Can't you think of something else to do?" And so she went in and made the beds and began to clean up. So it helped for her to do that. See, occasionally scolding works.

This incongruence between causality and action may be due to a lack of an integrated understanding of the older person's cognitive impairment, or may reflect the difficulty in maintaining a rational and/or objective perspective in the face of repeated or continuing problematic behaviors. This may also be related to the nature, degree, and duration of the older person's cognitive impairment. It may be very difficult to develop an integrated approach to managing problem situations if the older person's impairment is not always evident, or if it is variable. It is possible that the integration of causality with action can only occur after repeated demonstrations of cognitive impairment by the older person. This may happen only for those caregivers who are able to attribute causality appropriately to the underlying cognitive impairment, instead of "taking it personally".

Evaluation of responses. The evaluation of outcomes refers to the caregiver's ongoing appraisal of the effectiveness of her attempts to manage problematic situations, and the tolerability of the problematic behaviors and their sequelae. It is important to recognize that this evaluation is influenced by characteristics of the caregiver as well as the many variables involved in the process of managing the problematic situation. In addition, this evaluation represents the cumulative effects of managing repeated problematic situations. It is therefore too simplistic to assume that the evaluation of outcomes of any given intervention can be directly related to its effectiveness. Nor can tolerability be inferred directly from the decision for inaction, or the results of actions. Examination of the effectiveness of the intervention can, however, contribute to one's understanding of why some caregivers manage better than others, and why some situations are more or less tolerable.

A recurrent theme throughout this discussion of the management of problematic situations has been the extent to which the caregiver includes an understanding of the older person's cognitive impairment in her processing of information. Not suprisingly, the effectiveness of an intervention strategy may also depend on the extent to which the caregiver takes the underlying cognitive impairment into account when developing and implementing an intervention strategy:

> She wanted to go outside when it was cold. So I would say "come on, let's go in the kitchen and get something to eat." Sometimes she would forget about going out then...You redirect the thinking. As you know, they have a decreased attention span, so you use that to get them off the subject.

What is more, interviews with almost every caregiver indicate that not only is it important to incorporate an understanding of the cognitive impairment into one's management strategy, but a willingness to "go along" with the behavior, at least for a while, is key to successful resolution of the problem situation:

> When she gets upset and starts to hallucinate, I just play along.

> Sometimes he says he's gonna buy a new car so we just ask him "What kind?"

Some caregivers recognize that "going along" would result in more success, but have not yet fully incorporated that information into their management style:

> The neighbor called me and said "I have a little lost boy over here." He had gone over there and had told her that two men had come in and "made me sign my check over to them." He wanted her to call the bank. Well, she handled it better than I did; she pretended that she had called the bank. I told him there were no men, but he kept insisting there were. You can't explain it to them, you have to just go along with them.

Attempts at intervening which do not reflect an understanding of the older person's cognitive impairment tend to be less effective and frequently create distress for the caregiver:

> She loves to go, but she hates to stay long. The other night we went to dinner at my brother's...She kept saying "let's go," and I would tell her "it isn't time to go yet." But you see, she reasons; she figures out an excuse and says "the dog is in the car, she

> shouldn't be out there all alone that long." She comes up with reasons--not good ones because the dog can be out that long and doesn't give us any problems...but she doesn't listen to our reasons.

The concept of tolerability is extremely complex. There are many variables which seem to influence a caregiver's assessment of how tolerable certain behaviors and/or situations are. Although a number of references to the tolerability of specific behaviors or general situations were offered by the subjects interviewed for this study, a concise formulation for determining tolerability cannot be discerned from the data. One gets the sense, however, that the variables identified in this study do contribute, at least in part, to the caregiver's determination of tolerability. For example, the ability to attribute meaning to a problematic situation or behavior may make it more tolerable:

> M. was crying when it was time for her bath. The aide told me that M. didn't want to have her bath now, but that it was time. So I told her (the aide) it was not engraved in stone anywhere that the bath must be given at 9:00 and that she could just wait till 11:00 and try again. (M's behavior) was just a temporary rebellion... she was exercising her rights. She has so

> few rights that this rebellion is an attempt to exert them. She needs to win a battle every once and a while.

Here again, attributing the cause of a problematic behavior to the older person's cognitive impairment may increase a caregiver's tolerance for the behavior. By removing the element of intentionality from a behavior, it may be easier to accept or endure its occurrence:

> It's hard in the evening sometimes. If he could read he could entertain himself, but he can't read anymore. I wonder if it isn't some of the brain problem; it's not a problem with seeing. I read to him to get his mind off the situation.

Additional evidence suggests that tolerability may be related to the caregiver's expectation of the older person. Behavior which is contrary to the caregiver's expectations may be less tolerable than behavior which is consistent with the caregiver's assessment of the older person's abilities and pattern of behavior. Probably the most significant finding related to the concept of tolerability is the lack of a clear-cut explanation for what constitutes tolerable and intolerable situations. Behaviors which are calmly endured by some caregivers, create distress for others. What the analysis from this study suggests is that different ways of processing information about a perceived behavior may, under certain conditions, mediate a caregiver's evaluation that a behavior or situation is intolerable.

Chapter IV

Conclusions and Recomendations

The management of problems associated with the care of older persons with cognitive impairment is a growing concern in nursing. Current conceptualizations of this problem provide little direction for the development and implementation of effective intervention strategies. This study attempted to identify more clearly the variables and strategies which might facilitate family caregiving to older persons with cognitive impairment. This last chapter presents a summary of the methods and results from this study, along with the theoretical and clinical implications of the findings. Some of the limitations of the study and ethical considerations of the results will also be discussed. Finally, the potential utilization of the findings along with recommendations for future research will be suggested.

Summary of Methods and Results

This study employed grounded theory methodology in order to identify variables central to the management of behavioral problems associated with cognitive impairment. Using intensive interviewing techniques, fieldnotes were generated from a sample of family caregivers for older persons with cognitive impairment (n=6). The data were analyzed using constant comparative analysis (Glaser & Strauss, 1967) to develop a tentative theory regarding the management of individual problematic behaviors related to an older person's cognitive impairment.

The analysis of data indicates that caregivers who tend to be more successful in the management of problematic behaviors differ from those with less success in the ways in which they perceive and evaluate a behavior, and the process whereby they develop and implement intervention strategies. The ability of a caregiver to attribute causality of a behavior to the cognitive impairment, or to find personal significance in the behavior mediates her evaluation of the behavior as problematic. In addition, the caregiver's ability to integrate an understanding of the cognitive impairment into the development and implementation of an intervention will contribute to the efficacy of the intervention and is thought to influence the tolerability of certain behaviors. Other variables, such as caregiver characteristics, were also identified as playing a role in the management of problem behavior. Finally, it was acknowledged that there is insufficient data to understand completely the complexities of the concept of tolerability. However, concepts identified in this model are thought to relate to the determination of tolerability.

Theoretical implications

It is important to view these findings with respect to related theoretical frameworks. It was noted earlier that the process of data analysis included a review of literature relevant to the emerging theory. Refinement of the framework reflects some of the concepts from attribution theory. Attribution theory assumes that "by understanding naive or common-sense ideas about why people do the things they do, one can better predict the behavior and emotional reactions of people" (Frieze & Bar-Tal, 1979, p.2). Some of the original work on attribution theory by Heider (1958) proposes that a person's naive perception about the causes of his/her life events influence his/her reaction to them. By understanding one's so-called "common-sense psychology", attribution theorists maintain that behavior can be predicted. The data from this study suggest that differences in a caregiver's naive perceptions of behaviors (i.e., her attribution of causality and evaluation of the perceived behavior) relate to differential success rates in managing problematic behaviors. However, these data also suggest that the contextual variables associated with the behavior, characteristics of the caregiver, and the caregiver's ability to attribute meaning to the behavior also influence her reactions.

The study by Pratt et al. (1985) supports some of the findings from this study. They found that two internal coping strategies (confidence in problem-solving and reframing) were significantly correlated with lower levels of caregiver burden. Attribution of causality which reflected an understanding of the cognitive impairment and the ability to attribute meaning to a behavior may, in effect, be a demonstration of a caregiver's ability to reframe a problem. Likewise, it was noted that caregivers who managed problematic behaviors more successfully had a larger repertoire of strategies to change or interupt the behavior. Caregivers who manage more successfully may have more confidence in their ability to solve problems. Pratt et al.'s findings that lower levels of burden were associated with internal coping strategies may then be explained by a reduction in both the perceived and the actual burden of caregiving.

Finally, in order to understand the theoretical implications of the findings from this study, it is important to place the study within a larger context. The situation of families caring for an older person with cognitive impairment is very complex. The growing body of literature in the area offers a number of different frameworks for addressing the problems associated with chronic, cognitive impairments. As a result, any given research endeavor can focus on only a few of the aspects germane to this phenomenon. For example, researchers in biochemistry contribute to our understanding of cognition by concentrating on the interactive effects of neurotransmitters in the brain. In contrast, sociologists use a wider scope when analyzing general trends in caregiving which then influence the formation of health and social policy. Although each of these levels of analysis can contribute uniquely to our general understanding of family caregiving for older persons with cognitive impairment, conceptualizations which speak to phenomenon of interest in nursing are necessary in order to address the problems associated with family care of older persons with cognitive impairment.

This study focused on the identification of concepts which seem central to the caregiver's management of individual problem behaviors. By narrowing the focus of the study to the level of individual problematic behaviors, one risks losing sight of the bigger picture. Although it is reasonable to assume that a comprehensive understanding of the problems associated with family care of older persons with cognitive impairment cannot be achieved by simply adding up a list of problematic behaviors, this level of analysis does allow a better understanding of some of the discrete processes involved in managing problematic behaviors. This conceptualization of the process for managing problematic behaviors must then be viewed as only another piece of the puzzle, and not a solution to the whole puzzle.

Clinical Implications

Although it is premature to discuss the direct clinical applicability of the results of this study, it is important to evaluate the potential utility of this model for nursing practice. The distinctive feature of this model is the level of analysis it reflects. Previous research has tended to focus on either the older person with cognitive impairment, or the caregiver, rather than on the interaction between the two. By focusing on the behavior of the caregiver in relation to the behavior of the older person with cognitive impairment, it may be possible to intervene more effectively into the dynamics of the problem situation.

Several places in the model seem appropriate points for nursing interventions. For example, it might be possible to affect a caregiver's evaluation of the behavior by influencing her attribution of causality. Fostering a more insightful understanding of the underlying cognitive impairment and relating that to the older person's behavior may facilitate the development of intervention strategies which reflect a greater appreciation for the impairments. Similarly, attribution of meaning to certain behaviors may be encouraged, though this may be more difficult depending on the nature of the behavior.

Another place where nursing may be able to intervene is in the development and implementation of strategies to manage the problematic behavior. In fact, a particularly exciting finding relates to how one responds to behavior which is inappropriate to the occasion or inconsistent with one's own perception of reality. Caregivers who successfully managed problematic behaviors talked about "going along" with the behavior instead of trying to talk the older person out of it. In contrast, the approach most touted in the literature is "reality orientation". Reality orientation is essentially a behavioral modification strategy designed to "correct" the older person's perception of reality. My own clinical observations of this technique is that it is ineffective at best and cruel in certain circumstances. The data from this study suggest that "going along" with the problematic behavior leads to more successful resolution of the situation and causes less distress for both the older person with cognitive impairment and the caregiver. This finding is consistent with clinical observations by Rader, Schwab, and Doan (1985) which define problematic behavior, such as wandering, as "agenda behavior". They found that by going along with the older person's agenda by allowing enactment of the behavior (with nursing supervision), peaceful resolution is fostered.

This model offers a number of possible avenues for nursing intervention. The concepts related to intervention are not at a stage of development where they can be recommended for direct clinical application. However, by reframing the situation of family care of older persons with cognitive impairment to reflect the interaction between the caregiver and the older person, practitioners may gain insight into current practice problems to facilitate clinical management.

Limitations

Due to the nature of qualitative research methods, certain limitations of the findings must be addressed. The first is the size and non-random nature of the sample. The purposive sampling technique needed to identify key informants does not allow generalization of the findings to a larger population. In addition, this study has not yet reached a point of theoretical saturation through more focused data collection and analysis. Therefore, the concepts derived from the data must be considered tentative. Finally, these interviews focused only on the management of individual problematic behaviors and did not address other problems associated with the care of older persons with cognitive impairment.

Ethical Considerations

As with any research endeavor, it is important to consider some of the ethical issues raised by the findings of the study. The first concern relates to the focus on the caregiver throughout the model. By proposing that the caregiver's perception and evaluation of a given behavior influences her effectiveness in managing the problems associated with that behavior, it might be inferred that any problems which arise in caregiving are a result of the caregiver's perception. A fine but distinct line must be drawn between acknowledging that a caregiver may be able to act to resolve some of the problems she encounters in caregiving, and suggesting that she is responsible for the problems which are not managed successfully. Use of this framework to blame a caregiver for the difficult situation she were in would be considered an inappropriate interpretation of the concepts.

Another ethical issue alluded to earlier concerns the possibility of losing sight of the larger caregiving picture by focusing on individual behaviors. The author recognizes that a caregiver may be successful in managing all of the problematic behaviors encountered in caregiving and still find her situation intolerable. The complex nature of the concept of tolerability as well as caregiving in general has already been acknowledged. Still, the limitations of this framework in advancing a comprehensive understanding of the tolerability of family care for older persons with cognitive impairment warrants emphasis.

Finally, in a related concern, it is important to recognize that interventions designed to resolve individual problematic situations may, in the long run, be detrimental to a caregiver. With this type of approach one always risks curing the symptoms which are signals to a more severe illness. In other words, interventions which solve some of the smaller problems encountered in providing care to an older person with cognitive impairment may make it that much more difficult for a caregiver to extricate herself from a situation better handled in an institutional setting. Consequently, a better understanding of those factors which would indicate the need for nursing home placement of the older person with cognitive impairment is needed.

Potential Utilization

The potential utilization of this research has been addressed briefly in various parts of this report. However, a more succinct discussion is warranted. The ultimate goal of this planned program of research--this study being only the first step--is to develop nursing intervention strategies which decrease the burden on families who care for an older person with cognitive impairment. It is my belief that this goal is achieved most successfully through systematic development and testing of a framework which speaks directly to the nursing aspects of this clinical situation. The framework generated from this study will serve as the basis for continued research efforts in this area. The next step in the process is to further refine the concepts derived from these data through more focused interviews. That revised framework will then be used as the conceptual basis for a doctoral dissertation. The dissertation will be a methodological study designed to test the concepts and hypothesized relationships of the revised framework. It is hoped that this initial study will have provided the necessary anchor to maintain the clinical relevance of future research.

Future Research Recommendations

The next step in this planned program of research involves a more focused approach to data collection and anlaysis in an effort to further refine this conceptual framework. Questions from this phase of the research which remain unanswered include:

1. What caregiver characteristics are associated with successful and unsuccessful management of problematic behaviors?
2. What problematic behaviors are most intolerable?
3. What are the contextual variables which influence a caregiver's evaluation of a behavior as problematic?
4. How is the attribution of causality linked to a caregiver's emotional reaction to problematic behaviors?
5. How do caregiver characteristics and actions influence the occurrence/prevention of problematic behaviors?

In addition to the research planned as follow-up to this study, other research is needed in order to understand how best to address the problems associated with family care of older persons with cognitive impairment. Questions of particular interest in nursing include:

1. What services are most helpful to families caring for an older person with cognitive impairment? Under what conditions are they not helpful?
2. What are the risk and vulnerability factors which might indicate the need for nursing home placement?
3. How is the etiology of different cognitive impairment related to the occurrence of certain problematic behaviors? How might this influence the efficacy of intervention strategies?

Conclusion

The development of the knowledge base related to the nursing care of families caring for a cognitively impaired older person is still embryonic. Further research is necessary in order to conceptualize adequately the problems and strategies to manage them in a way that effectively directs the development of nursing interventions. The clinical merit of this study lies in its close relationship to the practice setting. Glaser and Strauss (1967) maintain that "generating grounded theory is a way of arriving at theory suited to its supposed uses" (p.3). Developing and testing nursing interventions from a framework derived through first-hand observations of the caregiving situation should maximize the clinical relevance they offer. It is hoped that by framing the process used by caregivers to manage the problems associated with cognitive impairment, with theory grounded in the empirical reality of the caregiving situation, nursing can become more responsive to the needs of family caregivers.

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Abstract

Management of Problematic Behaviors
By Family Caregivers for
Older Persons With Cognitive Impairment

Theresa A. Harvath

The management of problems associated with the care of older persons with cognitive impairment is a growing concern in nursing. Current conceptualizations of this problem provide little direction for the development and implementation of effective intervention strategies. This study attempted to identify more clearly the variables and strategies which might facilitate family caregiving to older persons with cognitive impairment.

Grounded theory methodology was used to identify variables central to the management of behavioral problems associated with cognitive impairment. Using intensive interviewing techniques, fieldnotes were generated from a sample of family caregivers for older persons with cognitive impairment (n=6). The data were analyzed using constant comparative analysis (Glaser & Strauss, 1967) to develop a tentative theory regarding the management of individual problematic behaviors related to an older person's cognitive impairment.

The analysis of data indicates that caregivers who tended to be more successful in the management of problematic behaviors

differed from those with less success in the ways in which they perceived and evaluated a behavior, and the process by which they developed and implemented intervention strategies. Caregivers who were more successful in their management of problematic behaviors reflected a more integrated understanding of the older person's cognitive impairment than those who experienced less success. In addition, caregivers who tended to perceive and evaluate the older person's behavior in terms of the underlying cognitive impairment had a larger repertoire of strategies from which to choose when managing problematic behavior.

It is hoped that by framing the process used by caregivers to manage the problems associated with cognitive impairment with theory grounded in the empirical reality of the caregiving situation, nursing can become more responsive to the needs of family caregivers.

Appendix A
Interview Questions

Sample of Open-ended Interview Questions

1. Could you tell me a little bit about some of the problems you have run into because of ______________’s memory problems?

2. What do you usually do when ____________ does that? Does that work? Why or why not?

3. What are some of the things that you have done to manage some of the problems you run into because of _________’s memory problems?

Appendix B

Consent Form

Oregon Health Sciences University
School of Nursing
Informed Consent

Investigation: Family Caregiving to Older Persons
With Memory Problems

Investigators: Patricia Archbold, RN, DNSc
(Thesis Advisor)
Theresa A. Harvath, RN, BSN
(Graduate Student)
Phone: 503-225-7877

Theresa Harvath, a graduate student in the School of Nursing, is doing a research project designed to understand more about how family members care for an older person who has memory problems. She wants to find out how caregivers help an older person who has memory problems to perform personal care tasks. She is also interested in how caregivers handle various problems associated with the loss of memory.

I understand that if I agree to participate in this project Ms Harvath will ask me questions about how I take care of ____________. She will also observe how I help him/her with tasks such as eating, dressing, or walking. The interview and observation session will take about 1-2 hours. I understand that more than one session may be needed. We will decide this at the end of the session. The interviews will be recorded in writing. All information will be handled to ensure confidentiality. Ms Harvath has agreed to answer any questions that I might have.

I understand that I may not benefit directly from participating in this project, but that it might help other people in the future. Some of the questions may touch on painful experiences which are upsetting to me. I understand that I am free to refuse to participate or to withdraw from this study at any time and it will in no way affect my relationship with, or treatment at, Good Samaritan Hospital and Medical Center, or the Oregon Health Sciences University.

There may be some benefits from participating in this study. It may be helpful to talk about my situation with a nurse who has experience with older persons with memory problems. Also, I might understand more about the things that I do to help ________ that are successful.

It is not the policy of Good Samaritan Hospital & Medical Center, or any other agency funding the research project in which I am participating, to compensate or provide medical treatment for injury. I should further understand that should I suffer any injury from the research project, compensation will be available only if I extaplish that the injury occurred through the fault of Good Samaritan Hospital, its officers or employees, or my physician. Further information regarding this policy may be obtained from the Office of Research Administration at 229-7218.

___ I have read and understand the foregoing and agree to be in the stud

___ I have had read to me and understand the foregoing and agree to be in the study

____

Caregiver's Name Date

Oregon Health Sciences University
School of Nursing
Informed Consent

Investigation: Family Caregiving to Older Persons With Memory Problems

Investigators: Patricia Archbold, RN, DNSc
(Thesis Advisor)
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There may be some benefits from participating in this study. It may be helpful to talk about my situation with a nurse who has experience with older persons with memory problems. Also, I might understand more about the things that I do to help ________ that are successful.

I understand that it is not the policy of the Department of Health and Human Services or any other agency funding the research project in which I am participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The University of Oregon Health Sciences Center, as an agency of the state, is covered by the State Liability Fund. If I suffer any injury from the research project, compensation would be available only if we establish that the injury occurred through the fault of the center, its officers, or employees. If I have further questions, I can call Dr. Michael Baird at 255-8014.

___ I have read and understand the foregoing and agree to be in the study

___ I have had read to me and understand the foregoing and agree to be in the study

____

Caregiver's Name Date