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FAMILY INVOLVEMENT IN ACTIVITIES OF DAILY LIVING FOR ALZHEIMER'S RESIDENTS IN LONG-TERM CARE SETTINGS

By

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ABSTRACT

FAMILY INVOLVEMENT IN ACTIVITIES OF DAILY LIVING FOR ALZHEIMER'S RESIDENTS IN LONG-TERM CARE SETTINGS

By

Retha Bragg

Family involvement with eight basic Activities of Daily Living (ADLs) was examined in this study: eating, dressing, combing hair or shaving, bathing, toileting, walking, getting in or out of bed, and moving in bed for institutionalized residents with Alzheimer's Disease (AD), identified as needing assistance with these activities. The sample included 86 former primary caregivers. Family involvement (FI) ranged from highly involved to not involved, with a mean FI score of 2.27 (number of ADLs families were involved in). The percentage of sample involvement was highest for eating, combing hair and shaving, and walking; and lowest for bathing, toileting, getting in or out of bed, and moving in bed. Generally, families remained involved with the resident's care. Results were discussed in terms of the relevant literature, limitations of the study, and implications for further research.

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my most ardent supporter, advocate, and confidante and partner;

and to my daughters Monifa and Malikah,

for graciously accepting "Thesis" as another sibling

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CHAPTER 1

INTRODUCTION, LITERATURE REVIEW, AND CONCEPTUAL FRAMEWORK

Introduction and Background

Chronic disease or disability often forces the elderly to rely on someone else for part or all of their care. Researchers expect that the number of elderly who have chronic illnesses and functional disabilities will grow significantly in the next decade, as a result of the current demographic population shift toward aging. Considerably more elderly people will require some degree of long-term home care (McCann, 1988). One consequence of the life span prolongation is an increase in the number of elderly with senile brain disease (Hirshfeld, 1983). Alzheimer's Disease (AD) or Senile Dementia of the Alzheimer's type is the most prevalent of the irreversible dementias. Alzheimer's Disease afflicts 5% to 10% of the population over age 65 (Mortimer, Shuman, & French, 1981). According to Cross and Gurland (1985), of the 4 million Americans who suffer with AD or other dementing disorders, approximately 1.5 million require constant care at home or in an institution. Based on these statistics, Cross and Gurland (1985) predicted that by the year 2040 over 7 million people will suffer from severe dementia.

Nearly 5% of our nation's elderly reside in nursing homes, and approximately 50% of nursing home residents have dementia (Hing, 1989). Although most families care for their relative with AD in the home setting, as the disease progresses the patient

becomes more dependent on others for assistance with the basic activities of daily living (ADLs), making continued home care very difficult (Gwyther and Matteson, 1983). Declining patient condition was cited by families as the primary contributory factor leading to institutionalization (Given, King, Collins, Elgood, and Berry, 1989).

The staggering cost of nursing home placement, combined with few resources for financial assistance, is another issue for those considering nursing home placement. It is estimated that nursing home placement costs more than $25,000 per resident, in most areas (Mace, 1991). Our government only provides long-term care for impoverished families (Mace, 1991).

In addition to the startling cost of institutional care, clients with AD or other dementing illnesses have more intensive care needs than those residents without these diagnoses. Their physical care needs include assistance with activities of daily living (i.e., bathing, dressing, toileting, transferring from bed to chair, remaining continent, and eating). Psychiatric and behavioral symptoms include experiencing delusions and hallucinations, wandering, physically hurting others and themselves, dressing inappropriately, crying for long periods, hoarding, getting upset, stealing, and exhibiting inappropriate sexual behavior (U.S. Congress, Office of Technology Assessment, 1992).

More specifically, families frequently cited the following concerns relating to nursing home environments: basic care needs may go unmet due to the resident's inability to verbalize their needs and the staff's inability to anticipate the client's needs such as hunger, pain, and thirst; inadequate exercise and physical movement; inadequate response by staff to the individual needs of clients; inadequate support of client's independence by staff performing care that the resident should be encouraged to do; and

failure on the part of nursing homes to meet the needs of the family (U.S. Congress, Office of Technology Assessment, 1992).

In summary, 50% of the institutionalized elderly have a dementing disease. Our society must explore the issues surrounding the provision of quality, affordable, and humane care that is acceptable and involves the family. Consistent involvement of the family with the institutionalized AD resident care is an area that remains overlooked (Mace, 1991).

Much research has been focused on family involvement in care of demented residents in the community. Traditionally, institutionalization has been viewed as the termination of family caregiving (Bowers, 1988). Therefore, institutions have not included family members in the planning and implementing of care. Buckwalter and Hall (1987) termed families of the institutionalized elderly as the "forgotten resource."

Many researchers have documented the continuation of family caregiving after institutionalization (York and Calsyn, 1977; Shuttlesworth, Rubin, and Duffy, 1982; Rubin and Shuttlesworth, 1983; Schwartz and Vogel, 1990). In their 1982 study, Shuttlesworth, Rubin, and Duffy concluded that conflict between the staff and family could result if both parties viewed themselves as primarily responsible for the care of the patient. At the other extreme, if family members withdraw to the periphery of the caregiver role and participate only as visitors, an adversarial relationship between family and staff may develop (Buckwalter and Hall, 1987).

Several researchers reported that the family is generally responsible for non-technical care, while the staff is responsible for technical care (Bennett, 1980; Black and Bengtson, 1978; Litwak 1977). These researchers defined technical care as tasks or behaviors that meet physical or material care needs; non-technical care was defined as care that is primarily psychosocial in nature. An overlapping topology of care was suggested by Dempsey and Pruchno (in press) because their study found that the technical and non-technical classification was too rigid. Bowers (1987) identified a classification of care based on purpose, which included protective care, preventative care, anticipatory care, supervisory care, and instrumental care. Bowers (1987, 1988) defined instrumental care as the performance of direct physical care tasks, and concluded that the most important type of caregiving behavior for the family was care that preserved the older person's self-esteem.

Studies by Dempsey and Pruchno (in press) and Bowers (1988) indicated an overlapping of tasks between family and staff. There were no studies in the literature that fully examined family involvement in activities of daily living (ADL) in the care of institutionalized AD residents.

Purpose

The focus of this research was to examine the frequency of family involvement in the ADLs of institutionalized AD residents who were identified as needing assistance with ADLs. Theoretically, ADLs are defined as physical care needs such as bathing, dressing, toileting, transferring from bed to chair, and maintaining continence (U.S. Congress, Office of Technology Assessment, 1992). The following ADLs were examined in this study: eating, dressing, combing hair or shaving, showering or bathing, using toilet, bedpan, or commode, walking, getting in or out of bed, or moving in bed.

Assistance with instrumental activities of daily living (IADL) (which includes money management, shopping, and housekeeping) was not the focus of this research.

While many researchers suggest that care provided to the long-term care resident should include the family as active partners, there remains a need to explore this area (Litwak, 1977; Rubin and Shuttlesworth, 1983; Bowers, 1988; Maas, Buckwalter, and Kelly, 1988, Shuttlesworth, Rubin, and Duffy, 1982; Schwartz and Vogel, 1990). Some studies have focused on the desired level of family involvement in the residents' post-institutionalization care, yet few have examined actual family participation in the delivery of basic personal care (Shuttlesworth, Rubin, and Duffy, 1982; Rubin and Shuttlesworth, 1983).

This issue is essential to the Gerontological Clinical Nurse Specialist (GCNS) for the planning and implementing of comprehensive care. Initially, the GCNS would need to perform a comprehensive baseline assessment to identify the resident's needs, and the desired nature and frequency of family involvement. Identification of potential barriers to family involvement is essential for a comprehensive assessment. Once barriers are identified, the GCNS, staff, and family can examine methods to either eliminate or decrease these barriers. Inclusion of the family communicates to them that they remain an important entity in the resident's life. Consideration of the family serves to decrease the family's stress with the nursing home placement (Gwyther and Matteson, 1983). This awareness allows the GCNS to clarify with the family their role and assist the family with achieving their desired level of participation. An optimum level of residential care could be delivered with family and staff working together (Litwak, 1977), resulting in increased family satisfaction. Also, with staff and family in harmony, the transition to the nursing home setting could become smoother for both the resident and the family (Litwak, 1977).

Family involvement is not static, but evolves over time. The GCNS, functioning as the coordinator of care, should perform ongoing evaluations of the care plan to ensure achievement of resident and family outcomes. As the liaison between staff and family (when issues or concerns are raised), the GCNS can assist the team in resolving concerns and developing mutually acceptable solutions that serve the resident's best interest.

Additional research produced in this area can assist nursing and long-term care facilities to improve the quality of care to the AD resident, reduce caregiver stress, and provide greater understanding between staff and families. GCNSs can support legislation and perform research that supports the collaboration between family and staff.

In summary, GCNSs can become the primary providers and coordinators of comprehensive care to the resident. Initially the GCNS can develop a climate of mutuality by involving the family in assessing, planning, and implementing the resident's care. As the coordinator of care, the GCNS can in-service staff and families, act as a catalyst for change to improve the quality of resident care, and promote collaboration between family and staff.

Clare Collins, Ph.D., performed a study at Michigan State University (1988–1992) funded by the National Institute of Mental Health (2 R01 MH41766-02-5) that examined the reactions of caregivers following the caregiver transitions of bereavement and institutionalization. She collected data by using a survey tool that identified basic care needs of residents and frequency at which family members were

assisting with the basic needs. For the present study, a secondary data analysis was performed using this data.

Research Questions

1. Among those residents identified as needing assistance with basic ADLs (eating; dressing; combing hair or shaving; showering or bathing; using toilet, bedpan, or commode; walking; getting in or out of bed; or moving in bed), what percentage of families are involved in assisting their relative with each of these activities?
2. Among families who report that they are involved in providing ADL care, what is the frequency of their involvement in each activity?

Theoretical Definitions of Variables

Long-Term Care Facility or Nursing Home: Any facility offering living accommodations, personal care, and in most instances some degree of health care to the elderly (National Center for Health Statistics, 1979). For the purpose of this study, nursing home or long-term care facility does not include an acute care facility or adult foster care home.

Family: Any caregiver related to the AD resident by birth or marriage. Family members were self-identified. The term also includes any person who was the primary caregiver prior to the admission of the client with AD to the long-term care setting (Collins, King, and Kokinakis, in press).

Activities of Daily Living (ADLs): Self-care abilities related to personal care, such as bathing, dressing, eating and continence (U.S. Congress, Office of Technology

Assessment, 1987). For the purpose of this study, basic ADL is limited to assistance with the following activities: eating; dressing; combing hair or shaving; showering or bathing; using toilet, bedpan, or commode; walking; getting in and out of bed; and moving in bed.

Family Involvement in ADL Care: For the purpose of this study, family involvement in ADL care is defined as how often a family member performs or assists with the eight basic ADLs identified above.

Conceptual Framework

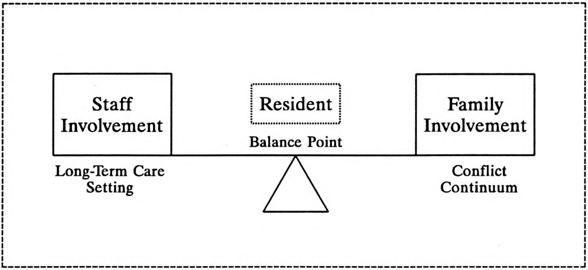
Litwak's Theory of Shared Function and Balanced Coordination was utilized to define the variable of family involvement with institutional care and to clarify the concept of family involvement in the institutional setting. According to Litwak, families not only have a right to remain involved in the care but they have an obligation to the resident for the provision of maximum-quality care. Litwak's theory provided clarification, definition, and a framework from which to view the variable of family involvement. Family involvement with resident care in the nursing home environment was examined in this study, with family involvement as the dependent variable. Essential to Litwak's theory was his concept of family involvement in basic care of the institutionalized elderly residents, and this concept was utilized in this research. Litwak's conceptual framework provides a basis for the conceptualization of family involvement consistent with this study's assumptions, because it assumes that families must be involved in the care of the resident to achieve maximum-quality care.

Litwak's theory proposes separate but coordinated functions or roles for the staff and the family in long-term care settings to provide the maximum quality of care to the resident. According to Litwak, the family should have a responsibility for providing non-technical care to the resident such as specific food preferences, applying make-up, and combing the resident's hair. Litwak borrowed from organizational theorists when he hypothesized that families are primary groups with the goal of meeting small-scale economies, whereas long-term care institutions are organizations with the goal of meeting large-scale economies (Litwak, 1977).

Clearly, families (primary groups) and institutions for the aged are antithetical structures. Therefore, when the two exist in the same environment there is constant conflict. This conflict should be seen as a continuum that need not be eliminated, but balanced. When families and staff are balancing the conflict, care is coordinated, resulting in the maximum quality of care (Litwak, 1977).

If either group dominates the other, many of the resident's care needs will go unmet, leading to a decrease in the quality of care. If the family or primary group is too distant (not involved in the resident's care), then the resident's care needs will not be met, resulting in a decrease in the quality of care. If the family is too close (over-involved in the resident's care or too demanding), this results in a decrease in quality of care for other residents. In both situations (too-distant or too-close family involvement) it is the responsibility of the institution to take corrective action (Litwak, 1977).

Figure 1. Litwak's Shared Function and Balanced Coordination Theory



Adaptation of Concepts of Litwak's Theory to the Present Study

This research was only concerned with the extent of family involvement in the eight basic ADLs of the institutionalized relative. Other aspects of Litwak's theory, such as nursing staff role and its coordination with the family role, conflict between family and staff, and the extent of the quality of care, were not the focus of this study. In contrast to Litwak, it is not an assumption of this study that all families must be involved in the care of their relatives after institutionalization. Limitations of Litwak's theory include inconsistency in the definition of non-technical care, failure to allow for the expansion of the family role, failure to identify how residents without family would receive quality care, and the assumption that all families desire or are able to remain involved in the resident's care (Litwak, 1977).

Review of the Literature

In general, research regarding family involvement in nursing home care has examined family involvement in terms of projected behaviors by the family or staff or both. When actual behaviors were examined, the resulting task list was extremely extensive, resulting in a 100-item task list of behaviors. Most of the research in this area was quantitative, except for Bower's qualitative studies, which sought to generate a new theory of conceptualizing care provided to dependent elders as perceived by their caregivers.

In comparison to the research on the caregiver role in the community, the research studies concerning the caregiver role in long-term care are few. York and Calsyn (1977) performed one of the first studies concerning this topic. One of the purposes of this study was to compare family involvement before and after nursing home placement of the elderly relative. The participants in this study were 76 patients (and their families) from three Lansing-area nursing homes. The instrument used for data collection was the Family Interview, which was a 45- to 60-minute instrument composed of both open-ended and closed-ended questions. The family involvement before and after nursing home placement were two of the seven areas assessed by the instrument.

Quantitative research methods were utilized to analyze the data. The findings of this research indicated that generally families did not separate themselves from their older relatives. A large proportion of families helped their older relative with a variety of tasks from shopping to physical care prior to nursing home placement. The families in this study tended to stay involved with their older relatives after placement in the nursing home. The researchers concluded that families tend to maintain patterns of involvement established before placement. Two limitations of the study were that: 1) only three nursing homes were utilized, and 2) this study only examined family involvement in terms of family visits to the nursing home and not in terms of actual hands-on care provided by the family members.

Shuttlesworth, Rubin, and Duffy (1982) utilized Litwak's balance theory as a theoretical framework in their descriptive study of role expectations as identified by nursing home administrators and families. The purpose of their study was to identify whom the nursing home administrators and the families of the residents deemed responsible for performing resident care tasks. The researchers developed a 100-item task list through an open-ended survey of the nursing home administrators and relatives of nursing home residents. This tool was used to analyze the data and was administered in person, by a group of administrators in training. The sample was a convenience sample of 56 nursing home administrators and 110 family members and relatives from 33 nursing homes located throughout Texas, including both intermediate and skilled-care facilities. Quantitative measures were utilized to analyze the data. The major finding of this study was that the administrators assigned the responsibility of keeping the resident well-groomed (e.g., bathing, showering, dressing, combing hair, and shaving) primarily to the nursing home staff. Of the relatives, 57.4% assigned the grooming activities to the nursing home, while 30.6% perceived these responsibilities to be a joint responsibility of both family and staff. It could not be determined by the information in the research article where the remaining ADL activities were categorized (e.g., walking, moving in bed). This study was limited in several ways. First, non-probability sampling procedures resulted in uncertainty about whether the sample was representative of the general population. Second, this study examined projected behaviors. There may be a difference between what people say they will do and what they actually do, but this study did not account for these possible differences. The tool utilized measured assigned behaviors. Perhaps the nursing home administrators were assigning behaviors to themselves because those behaviors were viewed as socially acceptable. Third, nursing staff working directly with the residents were not included. Fourth, only family members who visited on a regular basis were included. Family members who visited less regularly needed to have been included in the study in order to obtain information about the general population of family members of the institutionalized elderly.

To answer these limitations of the above study, Rubin and Shuttlesworth (1983) performed another study, in which non-administrative staff and relatives who visited less regularly were included. The inventory of 100 tasks was administered to 64 staff members (but mostly nursing staff: registered nurses [RNs]; licensed vocation nurses [LVNs]; and nurse aides [NAs]) at two nursing homes in Austin, Texas. Both of these nursing homes were intermediate and skilled facilities in an urban setting housing 100 beds.

Relatives were surveyed by mail; 137 surveys were completed and included in the sample. Prior to the mailing, relatives were subdivided according to the frequency of their visits and all were mailed the survey tool. Quantitative methods were applied to analyze the data. The staff assigned the responsibility of keeping the resident well-groomed (e.g., bathing, showering, shaving, dressing, and combing hair) as primarily the nursing home responsibility (78%). Again there was a discrepancy between the perceptions of the administrators and the relatives: 49% of the relatives assigned these duties to the nursing home and 45% considered these duties to be a joint responsibility. A limitation of this study was similar to the previous study, in that this study examined projected behaviors and not actual care given. Non-probability sampling procedures was another limitation.

Schwartz and Vogel (1990) applied Shuttlesworth, Rubin, and Duffy's (1982) inventory of 100 nursing tasks but modified the scoring procedure to indicate family, staff, or shared responsibility of tasks. The sample included eleven nursing homes. All of the nursing homes were urban, ten in California and one in Ohio. These facilities ranged in size from 45 to 172, with the mean bed size at 91. The tool was administered to ten percent of staff in four job categories: administrative (administrators, directors of nursing, etc.), direct support (RNs, LVNs, aides, activity directors, etc.), clerical (business office workers), and other support staff (maintenance, food service, housekeeping, etc.). A total of 142 responses was collected from the staff and 144 responses were collected from families or relatives. Quantitative methods were used to analyze the data. The basic ADLs of interest to the present study were not clearly indicated. Perhaps these activities were grouped under personal care. The staff rated personal-care tasks as more their responsibility, whereas the relatives indicated that they were willing to share in these activities. While this study examined desired or projected behaviors, it did not examine actual caregiving behaviors. Non-probability sampling procedures also limited the scope of this study.

Dempsey and Pruchno (in press) tried to determine numbers and types of tasks performed by the adult child of an institutionalized elder. This study differed from previous research because actual caregiving behaviors were examined. A purposive sample of 107 sons and 317 daughters of institutionalized elders was utilized. The sample was obtained through community outreach techniques and contact with area nursing homes. The methodology included use of an interview tool that identified 28 tasks essential to the daily life of the nursing home resident. These 28 tasks were previously identified in the literature. For each task, respondents were asked who was currently doing the task and whom they felt was responsible for the task: family, staff, or shared responsibility. Dempsey and Pruchno classified tasks as technical or non-technical based on the frequency of 70% or more of the respondents assigning the task to the family (non-technical) or to the nursing staff (technical). According to this definition, the following tasks relevant to the present study were classified as technical: using the toilet, eating, caring for appearance, bathing, dressing, and getting in and out of bed. Some items reflect overlap in that the task was performed by both the staff and family members (such as eating and caring for the resident's appearance). Approximately one half of the respondents (49.1%) reported that they did not perform any technical tasks and approximately one half (50.9%) reported that they performed one or more technical tasks. Based on these findings, Dempsey and Pruchno concluded that the conceptualization of family and staff responsibility into separate categories was inadequate. Instead, they suggested that an overlapping topology was more appropriate. Respondents (family members) in this study reported congruence between expected and actual role behaviors after institutionalization. Using the sample responses to identify the technical and non-technical duties was a major limitation of this study. Different samples may define technical and non-technical duties differently, making replication of this study difficult.

Bowers (1987) performed a study titled "Intergenerational Caregiving: Adult Caregivers and Their Aging Parents." Her work represents the only qualitative study on family caregiving resulting in a new topology. The purpose of this study was to view caregiving from the perspective of the caregiver and thus generate a new theory regarding caregiving topology. The research sample included 60 participants, 27 parents, and 33 of their offspring who lived in the community. Bowers utilized the "content comparative grounded theory" to obtain her sample of 27 parents and their 33 offspring. Most of the offspring were females and the primary caregivers. Data were collected through interviews that were taped, transcribed, and coded by the principal investigator. Caregivers and their parents were interviewed at home separately.

The methodology utilized in this study was grounded in dimensional analysis. Bowers, based on this research, showed that task-based categories are conceptually inadequate for understanding intergenerational caregiving. A dimensional analysis of the data revealed five conceptually distinct but empirically overlapping categories of family caregiving: anticipatory, preventive, supervisory, instrumental, and protective care. Instrumental care is defined with the traditional definition of caregiving, that is, hands-on caregiving behavior or tasks. Instrumental caregiving includes "doing for," "assisting," "providing," and "giving." The purpose of this care is to maintain the parent's physical integrity and health status. Under this topology, the basic ADLs were classified as instrumental care. This study was limited because it was not performed in a long-term care setting. Thus, it was not known if the findings could be applied to caregivers in the long-term care setting.

Bowers (1988) performed another study to test her topology in the nursing home setting. This study was performed in a 130-bed nursing home located in urban Wisconsin. Her sample included 28 family members who visited clients on an average of daily to every other week. As described by the families, residents were either not confused (46%), mildly confused (25%), moderately confused (14%), or severely mentally impaired (4%). It was not mentioned how many identified as confused had a diagnosis of AD. Bowers' findings indicated that her topology could be applied to families with residents in the long-term care setting. Again, the basic ADLs were classified as instrumental care. Families attributed the responsibility of these activities to the staff, but held themselves responsible as the evaluators of this care. Limitations of Bowers' study included the limited sample and setting, making it difficult to generalize the results.

To summarize, the previous research of family involvement in the basic ADLs is incomplete. The earliest study, by York and Calsyn (1977), indicated that families maintained a similar pattern of involvement with their relative after institutionalization. Nontechnical care was defined differently by different researchers. Studies by Shuttlesworth, Rubin, and Duffy (1982), Rubin and Shuttlesworth (1983), and Schwartz and Vogel (1990) indicated that families assigned some of the responsibility for performing the basic ADLs to themselves, whereas the staff assigned these duties as mainly a staff responsibility. The staff consistently discounted the desired level of participation by the families. Dempsey and Pruchno's study (in press) classified the basic ADLs as technical tasks, which were primarily assigned to the staff. This research supported the previous research because families assigned some of these tasks as joint responsibilities of family and staff, whereas the staff assigned the responsibility to themselves. Because families tended to share in many of the responsibilities of residential care, Dempsey and Pruchno concluded that the traditional technical and non-technical topology was inadequate. Bowers' studies supported Dempsey and Pruchno's work and generated a new topology in which the basic ADLs were classified as instrumental care. In her study, the family attributed the responsibility of providing the basic ADLs to the staff but held themselves responsible as the evaluators of the quality of this care.

What has not been fully examined in the previous research was the frequency of family participation in the provision of the basic ADLs to the resident. Examination of this area is crucial if nursing homes are going to integrate families as partners in care. Many researchers suggest that care provided to the long-term care resident should be shared between the staff and the family (Litwak, 1977; Rubin and Shuttlesworth, 1983; Bowers, 1988; Maas, Buckwalter, and Kelly, 1988; Shuttlesworth, Rubin, and Duffy, 1982; Schwartz and Vogel, 1990).

Another aspect that has been overlooked in previous studies is the provision of a concise definition of family involvement with care that reflects actual hands-on care. A concise definition of family involvement is imperative to support the linkage between research and practice. If the tool to measure family involvement is concise, it could eventually be used in the nursing home to assess and integrate families in the care. This study will provide a concise definition of family involvement, in the area of the basic ADLs, that reflects actual care given. The tool utilized in this study could be applicable in the clinical setting.

Summary

In summary, although there is a plethora of research on the caregiver role in the community, the caregiver role following the institutionalization of the AD patient has not been researched thoroughly. Dempsey and Pruchno's study (in press) was the most pertinent to this research project. In their study, the family's performance of the basic ADLs was examined in terms of percentage of sample involvement. They did not examine the frequency of that involvement, which the present research will do. Researchers have identified the need to generate additional knowledge involving the nature of the family caregiving role after institutionalization because: a) families continue to be dissatisfied with the nursing care in long-term care settings; b) ambiguity about the family caregiving role after institutionalization causes frustration and stress for family members; c) incorporation of the family in the care of the resident may improve the quality of care for the resident; d) there are not enough research studies that describe the role of the family members; and e) there are no studies that fully describe family involvement in the basic ADL caregiving behaviors after the institutionalization of the AD resident (Bowers, 1988; Maas, Buckwalter, and Kelly, 1988; Shuttlesworth, Rubin, and Duffy, 1982).

CHAPTER 2

METHODS, RESULTS, AND CONCLUSIONS

Overview

In this chapter the following information will be presented: research design, sample selection, data collection, procedures, instrument description and operational definitions, statistical methods for analysis of the data, results, interpretation of the results, significance to advance practice, and conclusions.

The research design was a retrospective descriptive study. The purpose was to describe the percentage of the sample that assisted with the ADLs of those residents who were identified as needing assistance with the ADLs, and to describe the frequency of family involvement with each activity of daily living after placement of a relative with AD in a long-term care setting. This study represented a secondary data analysis from a study titled "The Impact of Alzheimer's Disease on Family Caregivers" with Clare Collins, Ph.D., R.N., as the principal investigator.

The original study was a four-year longitudinal study of family caregivers of demented community residents. The study was performed at Michigan State University (1988–1992) and funded by the National Institute of Mental Health. The purpose of the original study was to examine caregiver reactions to providing care to a person with a dementing disease as they changed over time. Also, the reactions of caregivers were examined following the caregiver transitions of bereavement and institutionalization.

Sample

Criteria for Entry into the Longitudinal Study

The target population of the original study was family caregivers located through mailings distributed by local chapters of the Alzheimer's Association, Michigan Association of Adult Day Care Centers, and health-care agencies in Southwest Michigan. Data for the original study were collected as part of a four-year longitudinal study of the caregiving experiences of a convenience sample of family caregivers of persons with dementia (n = 338). The following criteria had to be met for a participant to be included in the original study: the caregiver was self-identified as the family member providing the most care to the relative with dementia meeting the following criteria: 1) the patient was at least 55 years of age; 2) the patient was dependent in at least one instrumental activity of daily living (IADL) and one basic ADL; 3) the patient had received a diagnosis of Alzheimer's Disease or other progressive dementia; and 4) the patient was a resident in the community at the time of entry into the study. Study participants were surveyed every 12–15 months during the data collection period by interviewers trained in survey methods (Collins, Given, Given, and King, 1988).

Sample for Current Analysis

The original sample included only families who provided community-based care. Ninety-eight persons institutionalized their relative during the course of the study. For the current study, a subsample of 86 was utilized, representing those participants who institutionalized their relative during the course of the original study and on whom complete data on study variables were available. A questionnaire that identified if the resident needed assistance with each ADL, and how often the relative assisted the resident with each activity on a five-point Likert scale, was used to collect the data. Significant demographic data was collected and will be presented in the findings. The strategies used to maintain subject participation in the panel are discussed elsewhere (Given, Keilman, Collins, and Given, 1990).

Data Collection Procedures

Subjects enrolled in this study participated in an extensive phone interview conducted by a trained research staff member. The original panel was contacted at a scheduled interview time. If they reported that their relative was institutionalized, they received an instrument specifically designed to survey aspects of their experiences before and after institutionalization. A mailing containing study instruments was also sent and returned to the interviewer by mail.

Participants who institutionalized their relative after entry in the study were interviewed at the next scheduled measurement point about their experiences in the three months before the institutionalization and their relative's care after institutionalization. Caregivers who placed their relative in an institution between the scheduled measures were interviewed an average of 12 months after the permanent placement of their relative.

Measures

The Instrument

In this study, operationalization of frequency of family involvement with basic ADL care was achieved by responses on the Modified Version of the Cornwell Involvement Inventory (Ellis, Given, and Given, 1989). The participants were asked if their relative needed assistance with a specific basic ADL. This survey tool had a two-part branching pattern for each of the eight ADLs. An example of the branching pattern using the activity of eating is:

Does your relative need help with eating?

____ No

____ Yes

If yes, how often do you help your relative with eating?

____ once a week or less than once a week

____ several times a week

____ once a day

____ several times a day

____ I do not help

The participants could respond positively to the first question but negatively to the second question. Therefore, one of the response choices included in the Likert scale was "I do not help." The eight basic ADLs were 1) eating, 2) dressing, 3) combing hair or shaving, 4) showering or bathing, 5) toileting or using bedpan or commode, 6) walking, 7) getting in and out of bed, and 8) moving in the bed. The tool measures the relative frequency of involvement of each of these activities (Appendix B). In this study, family involvement with basic ADL in the institutional setting was operationalized as scores on the Family Involvement in ADLs, identified above on the five-point Likert scale (Appendix B).

Reliability of the Instrument

A scale is composed of a set of items that measure a single attribute and nothing else. Reliability is one method for assessing the internal consistency of a scale. An instrument has internal consistency to the extent that all of its subparts are measuring the same characteristic. Cronbach's alpha is one of the most widely used formulas to test the reliability of an instrument. The coefficient alpha produces a reliability coefficient that is used to reflect the internal consistency of the instrument. The normal range of values of the coefficient alphas is between 0.0 and 1.0. The higher the coefficient alpha value the higher the degree of internal consistency the instrument has (Polit and Hungler, 1978). The alpha value for all eight items on the instrument was .64 and the standardized alpha for the eight items was .63, suggesting unacceptable levels of internal consistency. Together these eight items did not form a scale. Therefore, the data for each of the eight ADLs on the tool was analyzed separately.

This researcher assumed that those ADL items that were related to personal care and those related to mobility might form scales with an acceptable level of internal consistency. A reliability analysis was performed on those items that conceptually fit into a subgrouping of personal care (eating, dressing, combing hair or shaving, showering or bathing, and toileting) and those items that conceptually fit a subgrouping related to mobility (walking, getting in or out of bed, or moving in the bed) to determine if these items formed reliable subscales. The reliability analysis did not support the division of the personal care and the mobility items into separate subgroups. The alpha coefficient for the personal care items was .56 with a standardized alpha of .61. The alpha coefficient for the mobility items was .44 with a standardized alpha of .46. These low alpha values indicated that the personal care and the mobility items on the tool did not form reliable subscales. Therefore, no attempts were made to analyze this data as a scale.

Based on a review of the literature, the basic ADL items included on the tool formed a reliable scale when assessing basic ADL for elderly living in the community. The Katz Index of Activities of Daily Living, published in 1963, includes bathing, dressing, toileting, transfer, continence, and feeding (Gallo, Reichel, and Andersen, 1988, p. 67).

One possible explanation why the items on the tool formed a reliable scale in the community setting but failed to form a reliable scale in the institutional setting is because the family members are no longer the primary caregivers. In the home setting, if the relative needs assistance with multiple basic ADLs, the families are providing this care. In the institutional setting, there are many institutional barriers that may impede family involvement, such as restricted visiting hours, and institutional schedules designed to meet economies of a large scale. Thus, the staff are the primary caregivers and may perform many aspects of the resident's care before the arrival of the family or the visiting hours.

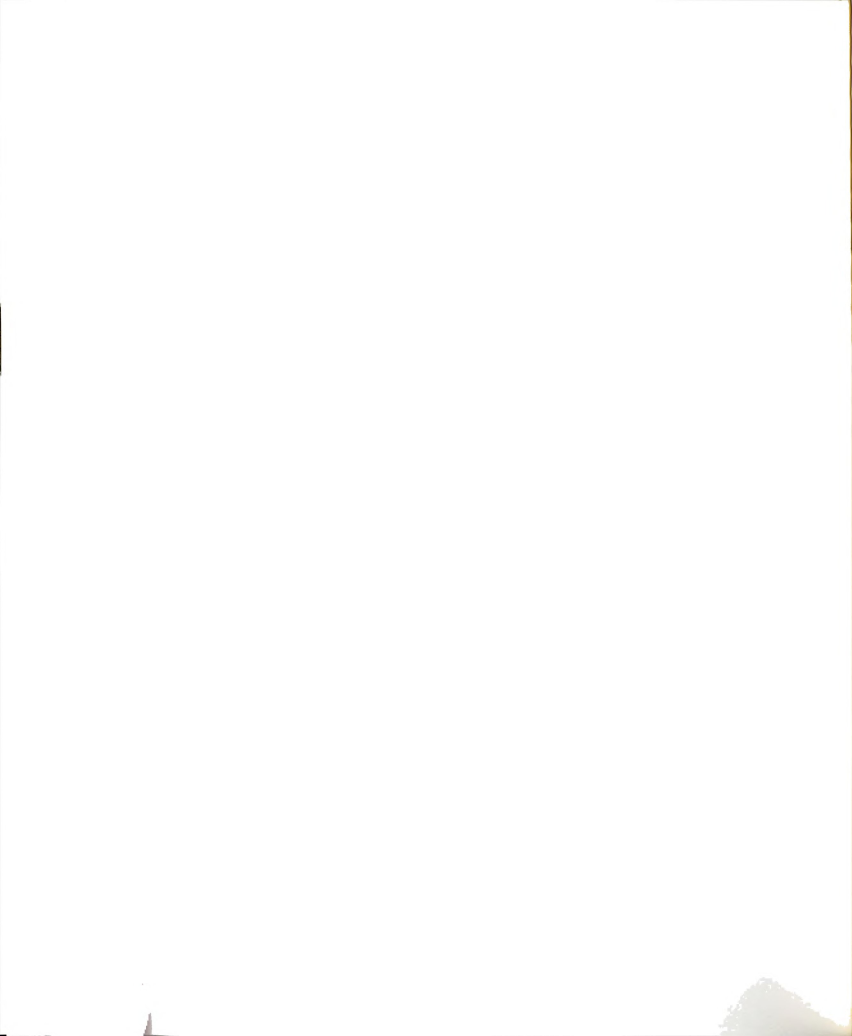
This tool has not been used previously to measure family involvement in institutional care. Psychometric properties have not been fully investigated for the tool in the institutional setting.

Protection of Human Subjects

The University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University approved the use of the original sample and approved the use of the data for this study (Appendix A). Each participant was informed that their participation in the study was voluntary, that they could withdraw at any time, and that the information would be held in confidence and not linked to them in any way. Caregivers signed a written consent form. At each subsequent interview participants were informed that their participation was voluntary. The data obtained from the surveys were coded for use with SPSS-X software and stored on computer diskettes at Michigan State University. Confidentiality of the original study was maintained by converting questionnaire answers to code sheets. The subsequent analysis for the present study was performed by computer and utilized the code sheets. This researcher did not have access to any identifying information of the participants nor access to the participants.

Statistical Analysis of the Data

The data were analyzed by using descriptive statistics. First, the demographic characteristics pertaining to the sample will be presented, which includes the caregiver, the long-term care resident, and the caregiving situation. The following characteristics are significant for identification of the caregiver: gender, age, income, education level,



and relationship to the long-term care resident. The long-term care resident characteristics are the diagnosis of AD or dementia. The gender and relationship of the caregiver to the long-term care resident will be presented as percentages. The caregiver age, education, and income level will be presented in terms of means, ranges, and standard deviations.

Each basic ADL that families responded to will be presented in terms of percentage of family involvement. This data will be presented in a categorical format with the percentage of responses reported for each activity, at each specified frequency identified on the tool. The total number of ADLs that families are involved in will be reported in terms of percentage of family involvement for each of the eight options.

Limitations

Several limitations of this study were related to the retrospective design. First, the secondary data analysis limited the study to the information previously collected and thus the information procured was not subject to manipulation by the researcher. The researcher could not ask questions other than those originally posed. Second, any flaws in the design of the research could not be corrected. Third, researchers who collect their own data develop an emotional tie or closeness to the study at the inception of the project, whereas this researcher eventually developed strong emotional closeness to the data only as the project progressed. A strong emotional attachment between the researcher and the study is important because many research projects require numerous hours, months, or years of work. Also, unexpected obstacles may develop during the course of any given research project. The development of a strong emotional attachment to the study empowers the researcher to be truly committed to the study through completion.

This study assumes that the family accurately represented the desires of the resident. This assumption may or may not be the case. Validation of this information was not feasible because the clients were confused and because this was a retrospective study.

Each questionnaire was completed by the participant. Measurement error may have been introduced if the participants did not understand the questions. A second limitation was the non-random sample. Thus, the ability to generalize the results to larger populations is dependent upon the degree to which the study sample reflects the general population of caregivers who institutionalize their elders. This sample was predominantly composed of white, middle-class subjects. Therefore, any results can only be generalized within this population.

Results

Sample Characteristics

A subsample (n = 86) was obtained from those participants who institutionalized their relative and completed the first half of all eight questions of the questionnaire. It is significant to report that the total sample was n = 86, but the n was fluctuating for each activity dependent upon those participants who reported that they assisted with that particular ADL. Those participants who did not complete any single question on the first half of the activity questions were deleted from the sample.

The majority of caregivers in the sample were women (70%), married (89%), and unemployed (63%), with a mean age of 64 years. Eighty-seven percent of the residents lived with the caregiver prior to institutionalization. Ninety-nine percent of the caregivers were Caucasian and 88% had at least a high school education. The mean duration of caregiving by the primary caregiver was approximately five years ($\bar{x} = 4.9$; SD = 3.0). Most of the residents were female (63%), married (61%), and Caucasian (99%). The mean age of the residents at the time of institutionalization was 75 years with a standard deviation of 7.3 years. The mean number of years since the resident's diagnosis was four years with a standard deviation of 2.5 years. The characteristics of the sample are portrayed in Tables 1 and 2.

Table 1
Demographic Caregiver Characteristics

Group	n*	%	Mean	SD
Sex				
Male	25	29.4		
Female	60	70.6		
Race				
White	84	98.8		
Black	1	1.2		
Education				
Grade School	4	4.7		
Some High School	6	7.1		
High School Graduate	23	27.1		
Some College	27	31.8		
College Graduate	12	14.1		
Graduate/Professional	13	15.1		
Employment Status				
Full-time	17	20.0		
Part-time	14	16.5		
Not Employed	54	63.5		
Relationship to Resident				
Spouse	50	58.8		
Child	24	28.2		
Child-in-Law	11	12.9		
Caregiver Lived with Resident Before Nursing Home Placement				
Yes	73	86.9		
No	11	13.1		
Marital Status				
Single	3	3.5		
Married	76	89.4		
Widowed	3	3.5		
Divorced	5	3.5		
Age of Caregivers			63.69	12.93
Duration of Caregiving in Years			4.91	3.90

*Total n in sample = 86; each subgroup adds up to only 85 because 1 response was missing.

Table 2
Resident Characteristics

Group	n*	%	Mean	SD
Sex				
Male	31	36.5		
Female	54	63.5		
Race				
White	84	98.8		
Black	1	1.2		
Marital Status				
Married	52	61.2		
Widowed	32	37.6		
Divorced	1	1.2		
Age at Institutionalization			75.12	7.33
Annual Household Income in Dollars			30,026.11	17,642.94
Duration of Diagnosis in Years			4.24	2.55
Duration of Symptoms in Years			7.25	3.17

*Total n in sample = 86; each subgroup adds up to only 85 because 1 response was missing.

Findings

1. Of those residents identified as needing assistance with any of the basic ADLs, what percentage of families were involved in assisting their relative with each of the following basic ADLs?: eating, dressing, shaving or combing hair, bath, toileting, walking, getting in or out of bed, and moving in bed.

2. Among families who report that they are involved in providing ADL care, what is the frequency of their involvement in each activity?

First, the total sample was n = 86, but the n was fluctuating for each activity dependent upon those participants who reported that they assisted with that particular ADL. Those participants who did not complete any single question on the first half of the activity questions were deleted from the sample. Therefore, percentages in this study were based on only those participants who reported that their relative needed help and that they assisted their relative with a particular activity. This lead to fluctuating n values for each activity, and sometimes resulting in small n values. Thus, caution must be taken when attempting to generalize the results to other populations.

Second, differentiation between the two measures of involvement (frequency of involvement and number of ADLs) was important. Both measures of involvement are interrelated but were viewed as different measures of involvement. Frequency of involvement refers to how often or time span (weekly, daily, several times a day, etc.). This concept was operationalized by the Modified Version of the Cornwell Involvement Inventory (Ellis, Given, & Given, 1989). Number of ADLs refers to the intensity of the involvement, i.e., how much or how many ADLs (1-8) families were involved in. These two measures are discussed separately.

Table 3 identifies the total number of ADLs the residents needed assistance with. Table 4 identifies those residents who either needed or did not need help for each of the eight basic ADLs. Together Tables 3 and 4 provide data that indicated that generally the residents were highly dependent on others for assistance with multiple ADLs. The mean of 5.57 (Table 3) supports this conclusion, indicating that the residents needed assistance with 5.57 ADLs from a total of 8 ADLs. Figure 2 depicts the data of Table 3 in a bar graph, clearly showing that most of the residents are clustered around needing assistance with 5–7 ADLs.

Table 3
Total Number of ADLs the Residents Needed Assistance With

Number of ADLs	% of Sample Involved	n
1.00	2.3	2
2.00	2.3	2
3.00	8.1	7
4.00	12.8	11
5.00	18.6	16
6.00	18.6	16
7.00	27.9	24
8.00	9.3	8
Totals	100.0	86

$\bar{x} = 5.57$; SD = 1.69

Table 4

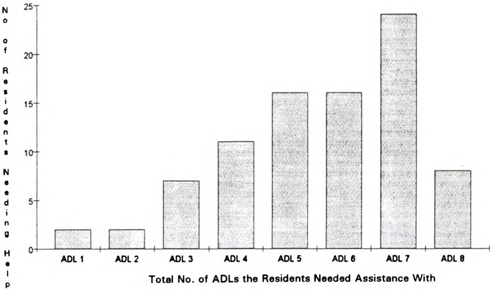
Number of Sample that Need and Do Not Need Help with Each ADL

ADLs (n = 86)	Help n	%	No Help n	%
Eat	62	72.1	24	27.9
Dress	79	91.1	7	8.1
Shave/Hair	84	97.7	2	2.3
Bath	85	98.8	1	1.2
Walk (n/a = 23 26.7%)	42*	48.8	21	24.4
Toilet (n/a = 31 36%)	41*	47.7	14	16.3
Bed/in/out (n/a = 5 5.8%)	48	55.8	33	38.4
Bed move-in	38	44.2	48	55.8

* = Discrepancy between those who responded in Table 4 and Table 5

n/a = not applicable (resident does not engage in that particular activity)

Figure 2. Total Number of ADLs the Residents Needed Assistance With



The percentage and frequency of family involvement in each of the basic ADLs are reported in Table 5. This researcher used 51% to differentiate those activities of high family involvement from those of low family involvement; if the percentage of family involvement in a particular activity was 51% or more, that activity was classified as an activity with high family involvement. Using this criteria, the following ADLs had a high percentage of family involvement or were activities that families were most likely to assist with: eating, shaving or combing hair, and walking. The remaining ADLs had a low percentage of family involvement or were activities that families were least likely to assist with: bathing, dressing, toileting, getting in or out of bed, and moving in the bed.

Table 5

Percentage and Frequency of Sample Active for Each ADL

ADL	1x wk	Several x wk	1x day	Several x day	Don't Help
Eat n = 62	n = 17 27.4%	n = 17 27.4%	n = 11 17.3%	n = 7 11.3%	n = 10 16.1%
Dress n = 79	n = 18 22.8%	n = 2 2.5%	n = 1 1.3%	----	n = 58 73.4%
S/Ha n = 84	n = 23 27.4%	n = 16 19%	n = 11 13.1%	n = 1 1.2%	n = 33 39.3%
Bath n = 85	n = 1 1.2%	n = 3 3.5%	----	----	n = 81 95.3%
Walk n = 41*	n = 12 29.3%	n = 10 24.4%	n = 3 7.3%	n = 5 12.2%	n = 11 26.8%
Toilet n = 42*	n = 8 19%	n = 7 16.7%	n = 1 2.4%	n = 2 4.8%	n = 24 57.1%
Bed/i/o n = 48	n = 4 8.3%	n = 2 4.2%	n = 2 4.2%	n = 1 2.1%	n = 39 81.3%
Bedm n = 37	n = 7 18.9%	n = 1 2.7%	n = 1 2.7%	n = 1 2.7%	n = 27 73.0%

* = Discrepancy between those who responded in Table 4 and Table 5

---- = No respondents in this category

Examination of the activities that families were most likely to assist with or that had a high percentage of family involvement (eating, shaving or combing hair, and walking) indicated some characteristics common among these activities, which may in some way explain why families assisted in these activities more frequently. These characteristics—multiplicity, independence, safety and pleasantness—were high among those activities that families were most likely to assist with.

Combing hair, eating, and walking are activities that are performed multiple times daily. This multiplicity may increase the likelihood that the family would be present when the opportunity to perform these activities was presented. Performance of these activities could occur, at least once, even in the presence of institutional barriers. For the most part, with the exception of walking, involvement in these activities would not cause harm to the resident or the family member. Walking could be a relatively safe activity depending on the mobility status of the resident. Therefore, performance of these activities was relatively safe for the family member and resident. These activities could be performed by the family member independently and with ease. All of these activities have a high degree of pleasantness, meaning that there was generally nothing unpleasant or distasteful associated with the performance of these activities.

Shaving is usually performed in the early morning in conjunction with the bath. Although shaving is usually performed once a day, it is an activity that may take extra time on the part of the staff. The finding that there was a high percentage of sample participation suggests that perhaps this was an activity that may have been omitted during the bath. The early morning prior to visitation is a very busy time for the staff and is traditionally the time when institutional staff are attempting to meet large-scale economies. Many residents may need bathing before breakfast. When this finding is examined in conjunction with the finding that 95% of the sample did not participate with the bath procedure, it can be inferred that shaving was omitted by the staff.

Examination of the activities with a low percentage of sample involvement or that families were least likely to assist with (bathing, dressing, toileting, moving in bed, getting in and out of bed) indicated that these characteristics (safety, multiplicity, independence, and pleasantness) were found to be of a low intensity.

First, the bathing and dressing are activities that are performed prior to or after the visiting hours, thus these activities did not have the characteristic of multiplicity. Bathing also has a low degree of safety and independence, because it requires knowledge of lifting and usually more than one person to administer a tub bath or shower. Second, after the bath is provided, the residents are usually dressed prior to the visiting hours. Litwak's concept of institutional barriers could be used to explain the very small percentage of family involvement in these activities.

The other activities (moving in the bed, getting in and out of the bed and toileting) require some knowledge of lifting, and perhaps more than one person to perform safely. These activities have a potential for injury to the resident and/or family member should a fall occur. Also, depending on the status of the resident, these activities may require the assistance of multiple people. In some nursing homes, families are not encouraged to lift or transfer the residents, due to the risk of injury and subsequent institutional liability. The physical labor involved in these activities may decrease the amount of pleasantness associated with these activities. Depending on the health status of the family member, it may be inappropriate or physically impossible for the relative to attempt to assist or perform these activities. Also, toileting is an activity that is not pleasant for the relative to assist with. Therefore, these activities have a low degree of independence, safety, and pleasantness, which may in some way explain why families were least likely to assist with these activities.

To summarize, the activities that families were most and least likely to assist with differed significantly when examined for the existence of four common characteristics (multiplicity, safety, independence, and pleasantness). Generally, activities that families were most likely to assist with shared these common characteristics to a high degree, whereas these characteristics were either absent or found to a lesser extent among the activities that families were least likely to assist with.

The two measures of FI were frequency (how often or time span), and intensity (how many ADLs). In terms of intensity of FI, the maximum number of ADLs that families assisted with was 6, with a mean FI score of 2.27. This FI mean score suggests minimal intensity of family involvement. It is significant to report that the FI mean score was adversely affected by those who were not involved at all in ADL care. However, of the total sample, 77.9% were involved in a range of 1.00 to 4.00 ADLs (Table 6). The highest intensity of FI was 6 out of 8 ADLs, suggesting a high intensity of involvement. It is also significant to report that no one in the sample was involved in 7 or 8 ADLs, suggesting a slightly lower level of intensity of FI after institutionalization, in comparison with an assumed intensity of 8 ADLs prior to institutionalization.

The second measure of FI was frequency (how often or time span). A wide variation in FI from highly involved to not involved was noted (Table 5). A small subgroup of families was highly involved, as indicated by the responses in the "1 x day"

and "several x day" columns. In contrast to those that were highly involved, there was another small subgroup of families that were not involved at all, as indicated by the responses in the "Don't Help" column. The majority of responses were in the "1x wk" and "several x wk" columns, indicative of moderate or regular FI across most ADLs. A consistent finding of the study was that the largest percentage of the sample was involved in most of the activities on a weekly basis (Table 5), while a smaller percentage of the sample was involved on a daily basis. In general, the once-a-week frequency had the highest percentage of sample involvement across all ADLs, with the exception of the bathing activity. Also, with the exception of the bathing and dressing activities, families assisted their relatives across all frequencies for each ADL (Table 5). Combined, the data in Tables 5 and 6 indicate that families remained involved in the resident's care at a variety of frequency and intensity levels.

Caregivers in this study were the primary caregivers prior to the institutionalization of the residents, suggesting that they were most likely involved with all aspects of the resident's care on a daily basis (high intensity and daily frequency). The above findings indicate that some families maintained similar patterns of involvement in terms of frequency (e.g., daily to several times weekly), while others deviated completely from their previous pattern of involvement (not involved), and others remained involved on a regular basis (weekly to several times weekly) but at a decreased frequency level.

It cannot be determined if high frequency is positively correlated to high intensity. Determination of this factor was not within the scope of this study.

Table 6
Total Number of ADLs the Sample Was Involved in

Number of ADLs	% of Sample Involved	n
0.00	11.6	10
1.00	22.1	19
2.00	27.9	24
3.00	17.4	15
4.00	10.5	9
5.00	8.1	7
6.00	2.3	2
Totals	100.0	86

$\bar{x} = 2.27$; SD = 1.53

According to Litwak (1977), institutional policies, rules, regulations, and staff attitudes are either barriers or facilitators to family involvement with resident care. Facilitators are institutional policies, rules, and regulations that promote and encourage family involvement. Institutional policies that subvert family involvement are termed barriers. Residents in this study were placed in a variety of nursing homes. It is not known to what extent the results were affected by confounding variables such as institutional policies and visitation hours, available parking, family lounges, staff attitudes, etc., which could either impede or support frequency of family involvement. It was not known to what extent the health status of the relative affected the frequency and intensity of family involvement.

In summary, the data on a sample of caregivers who assisted their relative with basic ADL care after institutionalization was presented. Because of the fluctuating

numbers of family involvement in each activity, which resulted in small numbers, caution must be taken when attempting to generalize these results to other populations.

Conclusions

The percentage and frequency of family involvement in basic ADL care for institutionalized AD residents was studied. An attempt was made to describe the type of activities and frequency and intensity of family involvement. Examination of the activities that had a high percentage of sample involvement, or that families were most likely to assist with (eating, shaving or combing hair, and walking) indicated a high degree of certain characteristics (safety, multiplicity, independence, and pleasantness) common among these activities, which may in some way explain why families assisted in these activities more frequently. These same characteristics were found to be of a lower intensity among those activities that families were least likely to assist with (bathing, dressing, toileting, moving in the bed, and getting in and out of the bed). Also, it was not known to what extent confounding variables affected the result of the study. Numerous confounding variables existed, such as institutional barriers and supports, health status of family members, and other obligations and responsibilities of family members.

A mean number of 2.27 ADLs that families assisted with supports the conclusion that families remained involved in the care of their institutionalized relative. Close examination of the data in Tables 5 and 6 indicated that many families were involved on a regular basis (weekly to several times a week) at moderate levels of intensity (assisting with 3–4 ADLs). According to the research, after institutionalization families tended to maintain similar patterns of involvement as prior to institutionalization (Schwartz and

Vogel, 1990). Therefore, this result of the present study is consistent with the findings of Schwartz and Vogel, because many families were involved on a regular basis (weekly to several times weekly) in many of the ADLs (Tables 5 and 6). The finding that a larger percentage of the sample was involved on a weekly basis in comparison to a smaller percentage of the sample being involved on a daily basis was consistent with research that indicated that families spend less time with the direct care of the relative after institutionalization (Moss, Lawton, Rajagopal, and Kleban, 1989).

The present study expands on previous research that indicated that some families perceived the performance of the basic ADLs to be a joint responsibility (Shuttlesworth, Rubin, and Duffy, 1982; Schwartz and Vogel, 1990) and departs from previous research that indicated that families perceived performance of these basic ADLs to be a staff responsibility (Bowers, 1988). Although this research was not designed to directly determine whom family deemed responsible for the basic ADLs, it can be inferred from the continued family participation that they accepted these activities as a joint responsibility.

Conceptual Model

Evaluating the study findings according to the concepts of Litwak's Shared Function and Balanced Coordination Model for family involvement in the nursing home setting indicates that families are involved in providing some non-technical aspects of the resident's care. The finding that family involvement in these non-technical aspects occurred most often at a weekly frequency, and that the family was more involved in some activities than others, may be indicative of institutional barriers that may have prevented higher frequency of participation across all activities. Another possible explanation is that some unexamined variables were responsible.

The Shared Function and Balanced Coordination Model is a valuable framework for the GCNS for a variety of reasons. First, Litwak's model could be used to facilitate family involvement at the onset of the resident's care by clearly defining the role of the family in the resident's care. Researcher's report that if family member involvement is initiated at the onset (when residents are first admitted to the institution), the likelihood of improved quality of care increases, because families feel that their efforts are both valued and welcomed (Schwartz and Vogel, 1990).

This model is also intended to coordinate and promote collaboration between families and staff. Recognizing that conflict between families and staff is natural, this model includes measures to decrease the conflict to minimum levels. The GCNS may utilize this framework to increase family satisfaction with long-term care. There is a plethora of data in current literature to support this goal of inclusion of families in the resident's care in the long-term care setting (Schwartz and Vogel, 1990; Dempsey and Pruchno, in press; Maas, Buckwalter, and Kelly, 1988; Bowers, 1988; Rubin and Shuttlesworth, 1983).

A weakness of Litwak's model is that it defines very rigidly the role of the family in non-technical aspects of care and provides inconsistent definitions of non-technical care. Litwak's model does not allow for expansion of the family role should subsequent research indicate this is necessary. Another weakness of his model is that it assumes that all nursing home residents have family. It does not explain how the resident without family would receive quality nursing care. Also, his model assumes that

all families want to be involved in the resident's care. There are situations (for example if the family member is in poor health or does not have adequate resources) when involvement of the family is contraindicated or not desirable. Litwak's model considers the family that is unable to be involved in the care as too distant and views the nursing home as responsible for getting these families involved in the care or bringing these families closer to the institution. In other words, a family's choice not to be involved in the care should be respected and not viewed as a negative. However, Litwak's model does not allow for providing quality nursing care in the absence of family involvement.

Recommendations for Future Research

The results of this study provided descriptive information regarding the eight basic ADLs that families continue to participate in at a specified frequency for each activity. This study needs to be replicated on diverse populations and on a larger sample to learn more about the general population of caregivers who continue to participate in the direct provision of ADL care of institutionalized elderly with AD. The actual n values fluctuated significantly for each ADL, resulting in a very small sample. Missing data was eliminated for those who did not answer the first half of each question. However, significant numbers in the sample did not answer the second half of each question, which decreased the sample size further. To alleviate these limitations, it is suggested that n = 100 for each ADL in which families are participating. Also, in terms of the responses on the frequency items, caution needs to be taken to ensure that the categories are mutually exclusive and that the questionnaire is answered completely and accurately. Some form of measurement error may have been introduced if the participants did not understand the question or answered the question inappropriately. To control for errors on the part of the participants in filling out the questionnaire, it is suggested that the participants complete the questionnaire in a controlled setting or have the tool administered by a trained researcher.

Future studies could also examine the barriers to family involvement across the activities and frequency levels. It is not known if the barriers to family involvement were institutional, personal, or a combination of both.

Also, a correlational study could be performed to determine if high frequency is correlated to high intensity.

Attempts were made to explain these results by using characteristics common to the activities that families were more and least likely to assist with. Perhaps future studies could determine if families have a preference for certain activities in comparison to others. Also, perhaps level 2 and level 3 studies could be performed to determine if there is a relationship between high intensity of involvement with high frequency of involvement.

Nursing Model: King's Theory of Goal Attainment

King's Theory of Goal Attainment is appropriate for working with families in the long-term care setting because the emphasis is purposeful interactions, with mutual goal setting for the achievement of outcomes. This theory predicts that if goal setting is mutual, outcomes will be achieved, resulting in client satisfaction.

In King's theory, nursing is defined as "a process of human interactions between nurse and client whereby each perceives the other and the situation, and through

communication they set goals, explore means and agree on means to achieve the goals" (King, 1981, p. 144). King also says that: "Nurses purposefully interact with clients mutually to establish goals and to explore and agree on means to achieve goals. Mutual goal setting is based on nurses' assessment of client's concerns, problems, and disturbances in health, their perceptions of problems, and their sharing information to move toward goal attainment" (King, 1981, pp. 142-143).

In addition to the above assumptions, King utilizes a systems approach. "Individuals are called ***personal systems*** [emphasis mine]. This means that the nurse as a person is a total system and the patient as a person is a total system" (King, 1981, p. 10). Two or more individuals interacting represent ***interpersonal systems***. ***Social systems*** are represented by society. Within any given society there are numerous social systems that influence social behavior, interaction, perception, and health (King, 1981, p. 11).

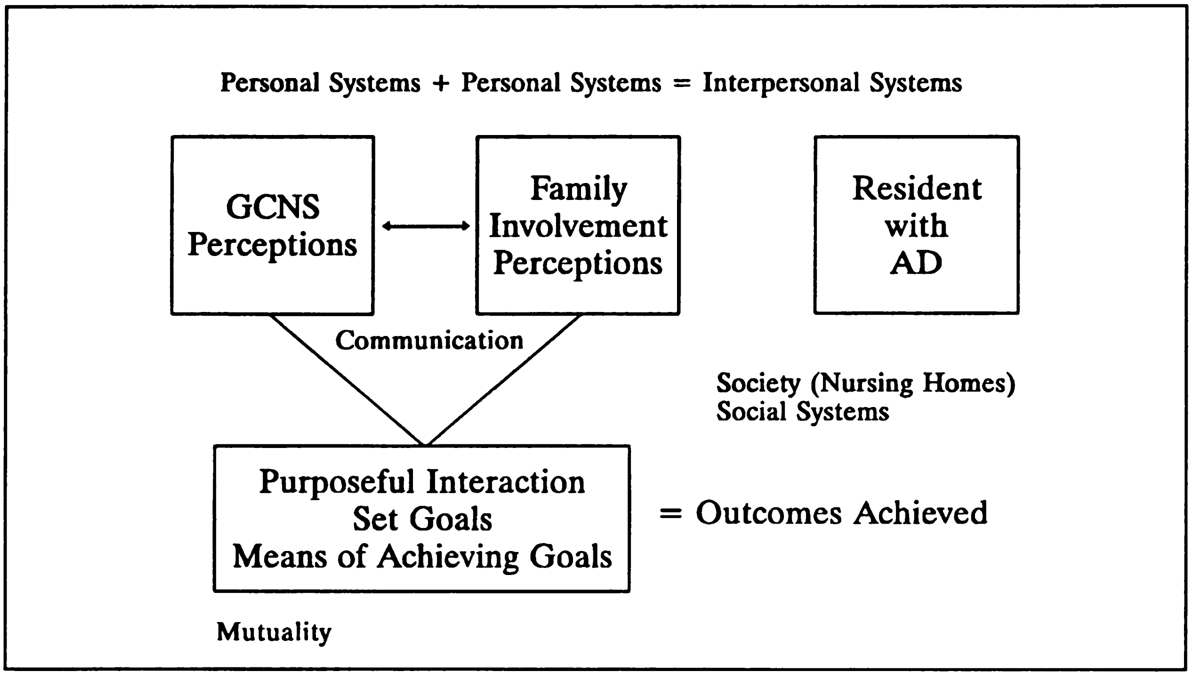
Integration of Study Variables Within King's Model and Nursing Interventions

While Litwak's Shared Function and Balanced Coordination framework identifies the roles of the family and staff as they collaborate in the provision of the resident care, King's Theory of Goal Attainment guides the GCNS in planning, implementing, and coordinating the resident's care, with utilization of the nursing process. Therefore, King's model could be used in conjunction with Litwak's model because both models view families as active care participants. Thus, implications for promotion of family involvement in resident care by the GCNS in the long-term care setting will be presented in the context of King's Theory of Goal Attainment.

The nursing home setting represents the social system in which the interactions will take place. The nurse, family, and client are the three personal systems. The nurse, resident, and the family are interpersonal systems interacting to achieve the maximum quality of care for the resident (Figure 3). Initially, the GCNS using King's theory recognizes that the social system of the nursing home, family, and larger society influences the outcomes of the interactions. The GCNS recognizes that placement of the relative in a nursing home setting may be a very stressful event for the family (Given, Collins, and King, 1987) and therefore the family's perceptual accuracy may be impaired. Thus, in purposeful nurse family interactions, methods by which the GCNS can assist the family with a reduction of the stress are mutually identified. The GCNS and the family communicate to identify and clarify perceptions, roles, goals and a means to achieve the goals. As goals are achieved, family satisfaction with care will occur. A major outcome of achieving goals is quality nursing care for the resident. The GCNS assesses, plans, implements, and evaluates the resident's care within a climate of mutuality with the family. Family satisfaction with care will occur if the goals are achieved. If goals are not achieved, then together the nurse, family, and staff reassess the plan of care and identify new goals.

Utilization of King's theory allows the GCNS to view the family as active partners or participants in the resident's care. Thus, plans for the resident are made in collaboration with the family. In nurse-family transactions, the family's perceptions may include feelings of love, relief, anger, and hostility regarding institutionalization (Gwyther and Matteson, 1983). The institution becomes the social system in which the transactions occur.

Figure 3. Integration of Study Variables into King's Model



Inherent within the institution may also be factors that impair or alter families' perceptions. For example, rules and regulations may represent sensory overload for the family. In initial transactions between the nurse and family systems, the family's perceptions of nursing care are identified. The goals of the nursing care are mutually identified. Finally, roles of the staff and family are identified in relationship to the client's care. Aspects of client care that are exclusive to both systems and mutual to both systems are clearly identified. Family involvement is encouraged and transactions with family are continuous.

Development of excellent rapport with the family provides a safe relationship in which the family is free to express perceptions. If the family's perceptions of the quality of nursing care are negative, the nurse and family can explore the basis for this perception. Together, transactions for improvement of the care are mutually identified. Also, the nurse's knowledge of the potential devastation of the institutionalization on the family system can be shared with the family. Nursing interventions include encouraging the family to participate in a family support group (Gwyther and Matteson, 1983). Measures to personalize the client's care are goals of transactions.

The basic building block of King's theory is mutuality. In initial transactions with the family, if the family decides not to be involved in the resident's care, this decision is respected. A major difference between Litwak's theory and King's theory is that King's theory recognizes and respects client's decisions. While Litwak proposes that all families must be involved, King recognizes mutuality and the rights of the clients as mutual decision makers.

A limitation of King's theoretical framework is that it assumes that all clients are alert and oriented. King does not provide any suggestions for situations where this is not the case. In terms of the present study, King's theory was appropriate, since the families were alert and oriented and may have accurately represented the desires of the resident.

Other nursing interventions for the GCNS include encouraging families to visit a variety of nursing homes before deciding on a particular one (Gwyther and Matteson, 1983). GCNSs need to encourage families to ask questions regarding the mission statements of the different institutions and to find out how particular institutions view the role of the family. Families need to be encouraged to ask questions regarding available supports. Families who would like to remain active in their relative's care should determine if the institution's goals and mission statement support such involvement. For example, does the nursing home have unlimited or limited visting hours? In contrast, families who are unable to be involved or who do not wish to be involved might ask how this is viewed by the institution. Ideally, for families who are unable to be involved or do not wish to be involved, institutions should respect this decision and not interpret it as a negative.

Several nursing interventions are related to the GCNS's role of primary provider and gate keeper to health care for the residents. As an expert practitioner, the GCNS must promote preventive health care which is acceptable, comprehensive, coordinated, and complete. Initially residents should be given a complete physical examination, which includes cancer screening. The subsequent physical examinations should be placed on a routine yearly schedule. Immunizations should be provided yearly. Nursing care plans should be focused or include measures to promote and maintain the resident's optimal functional status. Communication with the resident's primary physician is important to provide coordinated, comprehensive, and complete care.

Summary

The results of this study indicated that families remained involved with direct basic resident care in the long-term care setting, at a variety of frequency levels. The Gerontological Clinical Nurse Specialist in the long-term environment may use King's Theory of Goal Attainment to mutually involve families in the resident's care at levels that are agreeable to the family. This mutuality between the family and the nursing home environment will result in family satisfaction and quality nursing care. It is important that families who choose to be partners in the provision of resident care in the long-term care setting be respected and accepted. The GCNS may utilize King's theory to assess, plan, and evaluate the resident care within a climate of mutuality with the family. King's theory predicts that as the mutually purposeful interactions between nurse and families continue, goals are achieved and family satisfaction will occur. Acceptance of families as participatory partners in the resident's care is significant for maintenance of family involvement in the long-term care setting.

APPENDIX A

APPENDIX A

UCRIHS APPROVAL LETTER

MICHIGAN STATE
UNIVERSITY

April 14, 1993

TO: Ms. Retha Bragg
27240 Evergreen
Lathrup Village, MI 48076

RE:		
	IRB #:	93-184
	TITLE:	FAMILY INVOLVEMENT IN BASIC ACTIVITIES OF DAILY LIVING FOR ALZHEIMER DISEASE RESIDENTS IN THE LONG-TERM CARE SETTING
	REVISION REQUESTED:	N/A
	CATEGORY:	1-E
	APPROVAL DATE:	04/13/1993

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must seek updated certification. Request for renewed approval must be accompanied by all four of the following mandatory assurances.

1. The human subjects protocol is the same as in previous studies.
2. There have been no ill effects suffered by the subjects due to their participation in the study.
3. There have been no complaints by the subjects or their representatives related to their participation in the study.
4. There has not been a change in the research environment nor new information which would indicate greater risk to human subjects than that assumed when the protocol was initially reviewed and approved.

There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. Investigators must notify UCRIHS promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

If we can be of any future help, please do not hesitate to contact us at (517) 355-2180 or FAX (517) 336-1171.

Sincerely,

David E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Dr. Clare Collins

OFFICE OF
**RESEARCH
AND
GRADUATE
STUDIES**

**University Committee on
Research Involving
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(UCRIHS)**

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48824-1046

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APPENDIX B

APPENDIX B

MODIFIED VERSION OF THE CORNWELL INVOLVEMENT INVENTORY

[Listed below are the questionnaire items used in this study.]

4. Does your relative need help with eating?

___ NO (2) (Go to question #5)

___ YES (1) (Go to question #4a)

4a. If YES, how often do you help your relative with eating?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

5. Does your relative need help with dressing?

___ NO (2) (Go to question #6)

___ YES (1) (Go to question #5a)

5a. If YES, how often do you help your relative with dressing?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

6. Does your relative need help with grooming such as combing hair or shaving?

___ NO (2) (Go to question #7)

___ YES (1) (Go to question #6a)

6a. If YES, how often do you help your relative with grooming such as combing hair or shaving?

___ Once a week or less than once a week. (1)

___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

7. Does your relative need help with taking a shower or bath?

___ NO (2) (Go to question #8)

___ YES (1) (Go to question #7a)

7a. If YES, how often do you help your relative with taking a shower or bath?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

8. Does your relative need help with using toilet, bedpan, or commode?

___ NO (2) (Go to question #8a)

___ YES (1) (Go to question #9)

___ Not applicable, relative has catheter/uses diapers/is incontinent (3) (Go to question #9)

8a. If YES, how often do you help your relative to use toilet or commode?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

9. Does your relative need help with walking?

___ NO (2) (Go to question #9a)

___ YES (1) (Go to question #10)

___ Not applicable, relative does not walk (3) (Go to question #10)

9a. If YES, how often do you help your relative with walking?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

10. Does your relative need help with getting in and out of bed?

___ NO (2) (Go to question #10a)

___ YES (1) (Go to question #11)

___ Not applicable, relative does not get out of bed (3) (Go to question #11)

10a. If YES, how often do you help your relative with getting in and out of bed?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

11. Does your relative need help with moving in bed?

___ NO (2) (Go to question #11a)

___ YES (1) (Go to question #12)

11a. If YES, how often do you help your relative move in bed?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

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