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SATISFACTION WITH NURSING HOME CARE AND
CAREGIVER BURDEN AMONG FAMILY CAREGIVERS OF
INSTITUTIONALIZED ADULTS WITH DEMENTIA

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By

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ABSTRACT

SATISFACTION WITH NURSING HOME CARE AND CAREGIVER BURDEN AMONG FAMILY CAREGIVERS OF INSTITUTIONALIZED ADULTS WITH DEMENTIA

By

Kathleen A. Thomas

Family caregiving continues and feelings of burden associated with family caregiving can persist in the nursing home setting. The purpose of this study was to examine the relationship between family caregiver satisfaction with nursing home care and caregiver burden as measured by the Caregiver Reaction Assessment (Given, Given, Stommel, Collins, King, & Franklin, 1992). The sample was nonrandom, consisting of 97 white, well-educated family caregivers of relatives with dementia who resided in a nursing home. Impact on Schedule was negatively correlated with Satisfaction with Technical Care among family caregivers ($r = -25$; 2-tailed $p < .05$; $df = 92$) of nursing home residents with dementia. Caregiver Esteem was positively correlated with Satisfaction with Preservative Care among spouse caregivers ($r = .38$; 2-tailed $p < .01$; $df = 56$) of nursing home residents with dementia. Implications for practice and research are presented.

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Chapter I

INTRODUCTION

Advances in healthcare technology have lengthened the human life span. Consequently, our society is experiencing growing numbers of aging adults, many of whom have impaired cognitive ability and rely on others for assistance with activities of daily living (ADL) (Green, 1991; Weisensee & Kjervik, 1989; Williams, 1989). The care of adults who are unable to function independently is usually not provided by healthcare workers; approximately 75-90% of this care is performed by family caregivers (Brackley, 1992; Parker, Iversen, & Polich, 1989; Pierson & Irons, 1992; Weisensee & Kjervik, 1989).

The family caregiver is frequently a woman, such as the wife or daughter (Green, 1991; King, 1993; Temple & Fawdry, 1992), which is not surprising considering the nurturing role (Gilligan, 1982) and longevity of women in our society. Women tend to live longer than men, and therefore are more likely to be available to care for an impaired family member. Changing trends in family dynamics, including more women in the work force, high divorce rates, lack of geographical cohesiveness, and tendencies to bear fewer children later in life, have implications for family caregivers (Williams, 1989). Longer life spans may mean that the duration of the caregiving arrangement is increased, and smaller, geographically diverse families may mean that fewer family members are available to share caregiving responsibilities. The family caregiver, busy with a career or young children, coping with a divorce, or experiencing personal health problems, may find caring for a cognitively impaired family member difficult (Beach, 1993).

Family caregivers typically experience physical, psychosocial, and economic distress as a result of the burdens of caring for a family member with Alzheimer's Disease or other dementia's (Davis, 1992; Fletcher & Winslow, 1991; Given, King, Collins, & Given, 1988; Parker, et al., 1989). Interventions for family caregiver burden may include education, counseling, support groups, adult day-care, respite services, and nursing home placement of the care recipient (Lawton, Brody, Saperstein, & Grimes, 1989). Generally, family caregivers cope remarkably well with the burdens of caregiving. Institutionalization is a last resort that is often postponed until the physical or mental health of the caregiver is at risk (Collins, Given, & Given, 1994; Neundorfer, 1991; Pruchno, Michaels, & Potashnik, 1990; Smith, & Bengston, 1979).

Moving a family member to a nursing home, which has been described as a family crisis (Ferris, 1992; McFall & Miller, 1992), may create additional stress for the burdened caregiver. Family caregivers who place a relative in a nursing home may feel they are not fulfilling familial obligations and view nursing home placement as a breakdown in family unity (Cafferata & Stone, 1991/1992; Callahan, 1988; Duffy, Hepburn, Christensen, & Brugge-Wiger, 1989; Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991; Matthiesen, 1989). In a society that values freedom, justice, and individuality, nursing homes are viewed as places where elderly are warehoused following abandonment by their families; places where dependent adults are neglected, abused, and denied human dignity (Collopy, Boyle, & Jennings 1991). Despite these negative implications, nursing home placement of an elderly family member is common and has even been described as a normative transitional event in family development (Brody, 1985; Walsh, 1989).

Family caregivers of relatives with dementia may present to the primary healthcare setting with symptoms of stress related to caregiver burden. Interventions, such as adult day care or support groups, may be inaccessible due to lack of availability or economic barriers (Collins, King, & Kokinakis, 1994; Theis, Moss, & Pearson, 1994). The growth of home healthcare services may provide some relief for family caregivers, but it is not reasonable to expect that home care for individuals with dementia will replace the need for nursing home care. Current literature suggests that caregiver burden is not reduced following institutionalization (Barber, 1993; Dellasega, 1991; King, Collins, Given, & Vredevoogd, 1991; Pratt, Wright, & Schmall, 1987; Stephens, Kinney, & Ogrocke, 1991; Stevens, Walsh, & Baldwin, 1993). Based on current literature, primary healthcare providers may hesitate to recommend nursing home placement to family caregivers.

Continued caregiver burden among family caregivers following institutionalization of a relative with dementia is surprising considering the expectation that decreased responsibility for around-the-clock caregiving should reduce the burden among family caregivers. What are possible explanations for family caregiver burden following institutionalization of a relative with dementia? There are numerous variables which may effect the sense of burden experienced by family caregivers of demented nursing home residents (Brody, Dempsey, & Pruchno, 1990). Nursing home care is expensive; the usual private-pay cost often exceeds $100 per day. Insurance coverage, such as Medicare or other third party reimbursement, is frequently inadequate or nonexistent (Marion Merrell Dow, 1992). Medicaid pays for nursing home care only if the client is impoverished--often as a result of paying privately for nursing home care.

In addition to economic burdens, family caregivers devote significant physical and/or emotional energy toward the care of relatives in nursing homes. Family caregivers often maintain extensive contact with their relatives following institutionalization, continuing to participate in caregiving activities such as feeding, grooming, doing laundry, providing emotional support, and transporting relatives for ancillary healthcare services (Moulton, 1993; Stephens, et al., 1991; Stevens, et al., 1993). Furthermore, family caregivers of nursing home residents may grieve the loss of privacy and intimacy they enjoyed prior to institutionalization, and this grieving process may be emotionally burdensome.

This researcher has served as Director of Nursing in a small nursing home in western Michigan for fifteen years and has observed numerous family caregivers of nursing home residents. Many family caregivers of nursing home residents feel burdened relative to their caregiver role. Family caregivers may cry and admit to feeling guilty or powerless because they cannot continue to care for their relative at home. Nevertheless, this researcher has observed that most family caregivers acknowledge their limitations and accept the need for nursing home care.

For example, a 76 year old caregiver daughter had a 99 year old mother with dementia who resided in the nursing home. One day the daughter complained about her mother's care, telling this researcher that she had found her mother sitting slumped over in a bedside chair. The daughter assumed that her mother had been neglected by nursing home staff because it was obvious that her mother needed to lie down. The researcher comforted the daughter by explaining that, immediately prior to the daughter's visit, staff had offered to lay her mother down, but her mother refused. The daughter apologized tearfully, explaining, "It is hard to see Mom like this, but I can handle it . . . as long as I know she is taken care of."

This researcher proposed that a significant variable associated with family caregiver burden after a relative with dementia moves to a nursing home is lack of satisfaction with nursing home care. The research question was: **Is there a relationship between family caregiver satisfaction with nursing home care and caregiver burden among family caregivers of institutionalized adults with dementia?**

Chapter II

REVIEW OF THE LITERATURE

Family Caregiver Burden

Caregiver burden may be defined as the physical, psychological, emotional, social, or financial problems experienced by family members caring for impaired older adults (Gwyther & George, 1986). Caregiver burden may be objective or subjective. Objective burdens include the care-recipient's physical dependency needs, such as need for assistance with bathing, dressing, toileting, and feeding, or behavioral problems, such as wandering, inability to communicate, or resisting ADL assistance. Subjective burden is the caregiver's emotional response, such as feeling fatigued from constant caregiving demands or embarrassed by the care-recipient's idiosyncratic behaviors.

Negative responses, or burdens, seem to be the dominant reactions reported in the literature among family caregivers of relatives with dementia. In contrast, and commonly overlooked in the literature, family caregiving for relatives with dementia may result in positive reactions, such as enhanced feelings of esteem related to the caregiver role. Positive reactions to family caregiving seem reasonable considering the strong sense of responsibility and intimacy among family members (Given, et al., 1992). Lack of positive reactions to caregiving among family caregivers of relatives with dementia may be burdensome.

Caregiver burden may be defined relative to characteristics of the care-recipient or the caregiver. Characteristics of the care-recipient that may be burdensome include the diagnosis, such as Alzheimer's Disease, which is a common focus in the literature. Other diagnoses of care-recipients which have been reported in the literature relative to family caregiver burden include hip fractures, strokes, or cardiac disease (Vitaliano, Young, & Russo, 1991). Characteristics of the family caregiver that may affect caregiver burden include familial relationship to the care-recipient (i.e. spouse versus adult child), gender, employment status, economic resources, social support, and personal coping strategies (Vitaliano, et al., 1991).

Caregiver burden is likely to vary depending upon the availability and utilization of healthcare services such as nutritional support, respite services, Hospice care, adult day care, or home nursing services. Investment of healthcare dollars for intervention strategies and evaluation of these strategies may be based on family caregiver reactions. Family caregiver burden may be affected by healthcare policy, such as family leave legislation (Given, et al., 1992).

Caregiver burden has been described as uni-dimensional (Zarit & Zarit, 1987), but more recently is described as a multi-dimensional concept (Given, et al., 1992; Novak & Guest, 1989). Given, et al. (1992) developed the Caregiver Reaction Assessment (CRA) which includes five dimensions of caregiver reactions including, (1) caregiver esteem, (2) lack of family support, (3) impact on finances, (4) impact on schedule, and (5) impact on health. Caregiver esteem is a positive reaction to family caregiving, whereas the other dimensions of caregiver reactions are negative. Caregiver esteem is the extent to which caregiving provides a personal sense of reward and accomplishment; caregiving is enjoyable and does not cause resentment. Lack of family support is the extent to which the family works together so that the caregiver does not feel abandoned. Impact on finances is the strain on the financial situation of the caregiver associated with caregiving. Impact on schedule is the extent to which caregiving interrupts usual activities and the degree to which the caregiver's activities center on caregiving. The final dimension, impact on health, is the caregiver's physical strength for caregiving and adverse physical effects resulting from the caregiving experience.

The environment in which family caregiving occurs has not been examined sufficiently as it relates to caregiver burden; burdens of family caregiving may vary significantly depending upon whether the care-recipient is at home or in a nursing home. The literature relative to family caregiver burden is vast, but generally relates to family caregiving outside of an institution. There seems to be an implicit assumption that family caregiving ceases when institutionalized care commences, which is obviously a false assumption based on the continued involvement of family caregivers following nursing home placement (King, et al., 1991).

Representative samples of family caregivers have not been used to study caregiver burden in the nursing home setting. For example, Dellasega (1990) reported that family caregivers continued to experience caregiver burden following nursing home placement. Dellasega's results can not be generalized to family caregivers of nursing home residents because the sample consisted of caregivers who were participants of a caregiver support group. Family members who attend a caregiver support group may experience caregiver burden differently or utilize different coping styles than the general population of family caregivers of nursing home residents. Despite limitations in Dellasega's sample, numerous other studies (Barber, 1993; King, et al., 1991; Pratt, et al., 1987; Stephens, et al., 1991; Stevens, et al., 1993) support the notion that family caregiver burden continues following nursing home placement of the care recipient.

The experience of family caregivers of nursing home residents has not been adequately explored. It is clear that family caregivers continue to function in a caregiver role and continue to experience caregiver burden after institutionalization of their family member (Johnson, Morton, & Knox, 1992; Ross, Rosenthal, & Dawson, 1993; Stevens, et al., 1993). Continued caregiver burden following institutionalization seems to contradict the logic that reduced responsibility for hands-on care will relieve caregiver burden. Considering the significant investment of healthcare dollars in nursing home care, continued burdens among family caregivers of nursing home residents is disturbing.

It is reasonable to assume that the burdens of family caregivers outside the nursing home differ from the burdens of family caregivers following institutionalization. Describing and explaining the reactions of family caregivers of nursing home residents is prerequisite to designing effective interventions. This study aims to improve understanding of family caregiver reactions following nursing home placement of a demented relative.

For the purpose of this study, caregiver burden among family caregivers of institutionalized adults with dementia was defined relative to two dimensions of caregiver reactions: caregiver esteem and impact on schedule. Caregiver esteem may be related to nursing home satisfaction because the family caregiver has contracted for nursing home care as a substitute for family caregiving. The nursing home, as a surrogate for family in-home care, is providing care which the family would provide if the family caregiver were not too burdened to persevere. If the family caregiver is satisfied with nursing home care, the family caregiver may feel that their caregiving responsibility has been fulfilled. If the family caregiver is not satisfied with nursing home care, the family caregiver may feel a sense of low caregiver esteem due to failure to arrange adequate care. Therefore, satisfaction with nursing home care infers quality family caregiving, which has implications for the esteem of the family caregiver.

Impact on schedule may be related to nursing home satisfaction because a family caregiver, dissatisfied with nursing home care, may visit the nursing home frequently to monitor nursing home care or provide hands-on care that is perceived to be inadequate in the nursing home. Traveling to and from the nursing home to monitor care may become the central activity in the family caregiver's schedule and may interfere with other activities. The family caregiver who is satisfied with nursing home care may visit when convenient, not based on a schedule of perceived caregiving demands.

Furthermore, the family caregiver who is satisfied with nursing home care may feel comfortable limiting the frequency and duration of nursing home visits, thus resulting in less impact on their daily schedule.

Family Caregiver Satisfaction With Nursing Home Care

Society views nursing homes unfavorably in terms of quality of care. Not only has government regulation of nursing homes been ineffective in assuring nursing home quality, government over-regulation of nursing homes has added barriers to quality in nursing home care (Collopy, et al., 1991). There is an impetus in healthcare to improve quality by focusing on outcomes, one of which is client satisfaction. Unfortunately, literature about quality in nursing home care continues to focus largely on structure and process criteria, such as staffing ratios and infection control practices (Bliesmer & Earle, 1993; Menzey 1989; O'Leary, 1992). A few studies have attempted to elicit resident satisfaction with nursing home care (Kane, 1983), but these studies are obviously limited to subjects who are able to respond in a meaningful way, which excludes large numbers of nursing home residents with dementia. Family caregivers of nursing home residents continue to be involved in a caregiving role following institutionalization, monitoring nursing home care to assure quality. Therefore, quality of care for nursing home residents with dementia may be assessed based on family caregiver satisfaction with nursing home care.

Family caregivers often function as surrogate decision makers, formally or informally, for nursing home residents, particularly those with dementia (Corcoran, 1993; Montminy, 1990). The ethical presumption is that family caregivers are likely to know the wishes and sensibilities of their relatives and to make decisions in their relatives' best interests (Kapp, 1991). Family caregivers of nursing home residents with dementia often determine where the client lives and whether care is satisfactory. The literature suggests that families may be generally dissatisfied with nursing home care (Collins, Stommel, Wang, & Given, 1994).

Prawitz, Lawrence, Draughn, & Wozniak (1991) found that family caregivers of nursing home residents in general (not just those with dementia) were more satisfied with nursing home care after they investigated several homes and family members agreed about the home selected. Family caregivers were generally less satisfied when they were forced to make an immediate decision about placement, felt they lacked sufficient time to investigate homes, and chose the first home with space available. This researcher found no references in the literature that reported family caregiver satisfaction with nursing home care among family caregivers of relatives with dementia.

Since family caregivers function as surrogate decision makers for nursing home residents with dementia, it is reasonable to review literature that describes nursing home residents' satisfaction with nursing home care. The assumption is that, since the family caregiver is acting as a surrogate decision maker, the family caregiver will accurately judge qualities in nursing home care consistent with the resident's sensibilities if the resident were able to assess or communicate her or his own satisfaction with nursing home care. A further assumption is that the family caregiver values qualities in nursing home care similar to those that the demented nursing home resident values.

Satisfaction with nursing home care is a subjective variable that is based on cultural values and beliefs. Knox & Upchurch (1992) found that nursing home residents value the following aspects of nursing home care (listed in descending order): family and visitors, clean and comfortable surroundings, good food, caring staff, feeling useful, affection, religious activities, social activities, flexibility in daily schedule, and privacy. Joiner & Freudiger (1993) used the Home Satisfaction Scale which asks residents to rate the following phases of life in the institution: food, medical care, rules and regulations, cleanliness, living quarters, religious activities, recreation, and employees in the home.

Bowers (1988) described two dimensions of caregiving in nursing homes--technical and preservative. Either technical or preservative care may be provided by family or facility caregivers. Technical care involves providing for physical or material needs of the resident which may be provided by the family caregiver but is usually expected of nursing home staff. Bowers reported that families perceive technical expertise as prerequisite to satisfactory nursing home care. "Families expect staff to have technical knowledge about medications, disease processes, . . . as well as technical skills for performing skilled procedures. . . .Failure to recognize symptoms of an accelerated or new disease process, or the side effects of medications was consistently interpreted as evidence of poor quality care . . . Safe and efficient transfer of a resident from bed to chair or toilet were consistent expectations (Bowers, 1988, p. 365)."

Preservative care refers to care which aims to preserve the nursing home resident's sense of self and is often performed by family caregivers. The purposes of preservative care include maintaining family connectedness, resident dignity, resident hopes of recovery, and resident control of the environment. Preservative care includes psychosocial tasks such as reminiscing, personalizing the resident's room, celebrating birthdays, selecting and caring for clothing, and reading and writing letters (Bowers, 1988).

Family members may view the performance of technical care by nursing home staff as a threat to their more important aim of preservative care. For example, nursing home staff may encourage a resident in self-feeding with the aim to rehabilitate or maintain functional ability (technical care). Family caregivers may prefer that nursing home staff feed their relative to avoid spillage of food during self-feeding which may be perceived as undignified (preservative care). Family caregivers of nursing home residents may attribute responsibility for the performance of most tasks to the nursing home staff, but hold themselves responsible for monitoring and evaluating the quality of care and providing the staff with biographical information which enables staff to provide preservative care (Bowers, 1988).

Family caregivers of nursing home residents expect that satisfactory preservative care can exist without satisfactory technical care, but preservative care is an essential component of satisfactory technical care (Bowers, 1988). Thus, family caregivers do not expect themselves to be technically proficient, but family caregivers do expect nursing home caregivers to treat residents as uniquely human individuals, based on input from family caregivers. For the purpose of this study, satisfaction with nursing home care was defined as the family caregiver's perception that the nursing home was providing an acceptable level of preservative and technical care.

Hypotheses

The following hypotheses were tested in this study:

1. Family caregiver satisfaction with preservative nursing home care is positively correlated with caregiver esteem.
2. Family caregiver satisfaction with preservative nursing home care is negatively correlated with impact on schedule.
3. Family caregiver satisfaction with technical nursing home care is positively correlated with caregiver esteem.
4. Family caregiver satisfaction with technical nursing home care is negatively correlated with impact on schedule.

Chapter III

THEORETICAL FRAMEWORK

Neuman's Systems Model is the conceptual framework which guided this study. Betty Neuman, the nurse theorist who developed Neuman's Systems Model, had a background in mental health nursing and her model is useful for studying family caregivers of dementia clients. Neuman's Systems Model is one of open systems in which complex elements are organized and interacting. The client system is viewed as concentric rings surrounding a central core (Figure 1). The core contains basic survival elements and usual patterns of response. Lines of resistance immediately surround the core and function to protect it. The outer-most ring, called the flexible line of defense, protects the normal line of defense, which surrounds the lines of resistance and represents the usual state of wellness. The client system is composed of protective elements categorized within five variables--physiological, psychological, sociocultural, developmental, and spiritual--which are contained in all client systems and exist in each line of resistance and defense

(Neuman, 1989). The client system may include individuals, groups, such as families, or entire communities.

According to Neuman's Model, health is perceived as a continuum based on energy. The extremes on the continuum are optimal wellness, with maximum available energy, and death, which is total energy depletion. When elements of the system are in harmony, balanced, or stable, energy is conserved, and wellness is optimized. Energy may be maximized by strengthening any of the lines of resistance or defense. When stressors from the internal, external, or created environment impact upon the system, energy is used to maintain stability. If energy supplies are insufficient to maintain stability, stressors penetrate the normal line of defense, and wellness is compromised. If stressors penetrate the core, serious illness or death occurs (Neuman, 1990).

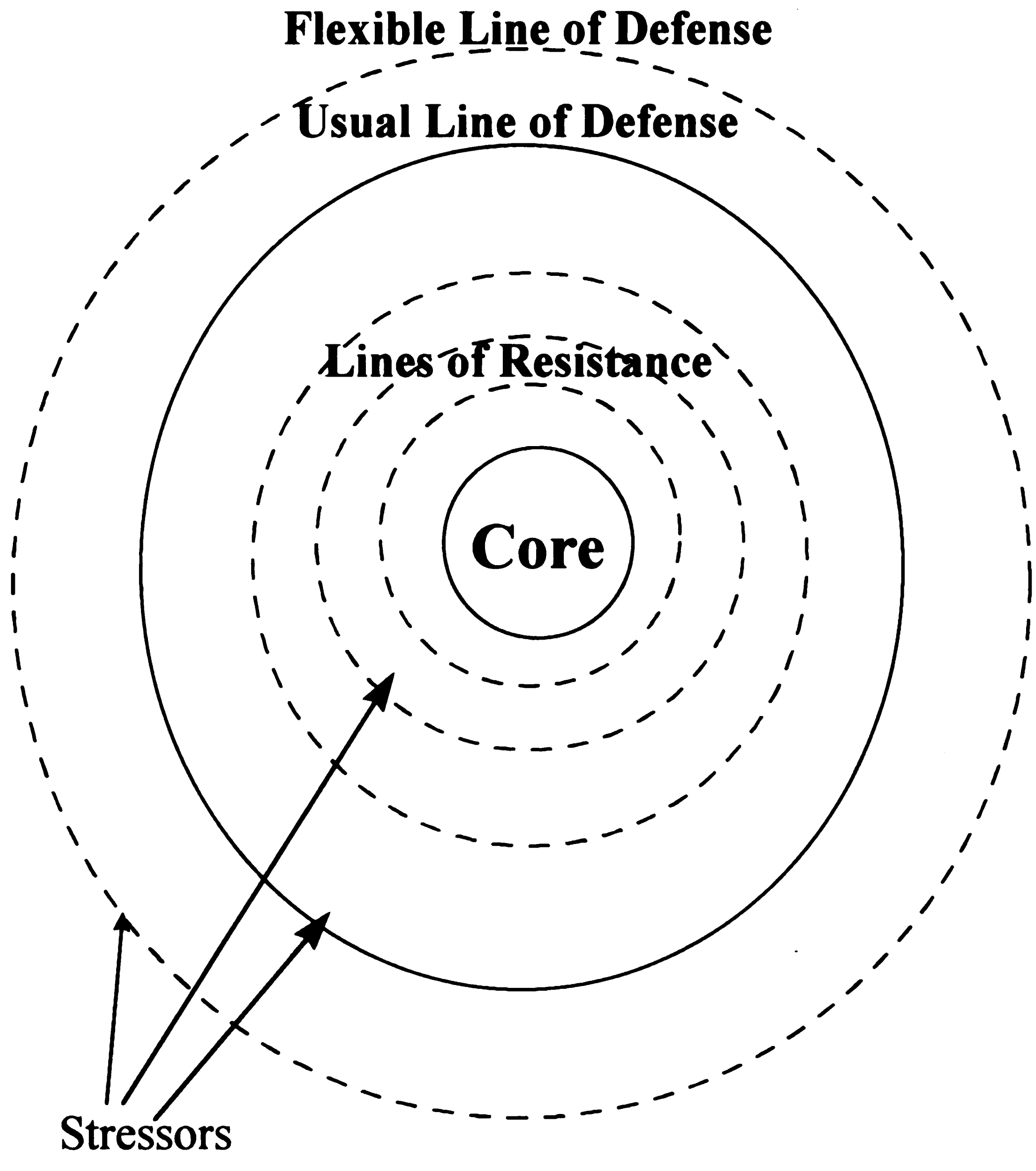

Figure 1 Neuman's Systems Model

The environment is defined as all factors surrounding the client system. The relationship between the client and the environment is reciprocal or circular in nature, including input, output, and feedback. Neuman defines three environments--internal, external, and created. The internal environment includes all forces contained within the boundaries of the client system. The external environment includes all forces outside the boundaries of the client system (Neuman, 1989). Neuman defines the created environment as, ". . . the protective, unconsciously derived environment that exists for all clients . . . The created environment, which includes elements of both the internal and external environments, acts as an intrapersonal protective shield or safety net against the reality of the internal and external environments; the true nature or reality of client and environmental exchanges (1990, p. 129)." Although elements of the created environment conserve energy by protecting the system, the created environment may become the source of stressors relative to the degree that the created environment offers protectiveness for the system.

The internal, external, or created environment is the source of stressors which are "tension-producing stimuli or forces (Neuman, 1989, p. 23)" that impact upon the client system, potentially disrupting system stability. Stressors may be known or unknown, real or potential. More than one stressor may occur simultaneously, and any stressor influences the client's reaction to other stressors to some degree. Stressors may vary in intensity, and the impact of similar stressors may vary depending on system resistance (Neuman, 1989).

According to Neuman (1989), primary, secondary, and tertiary levels of prevention as intervention may be implemented to promote, maintain, or regain optimal wellness. Primary prevention includes interventions which mitigate potential stressors or strengthen system defense against stressors. Secondary prevention includes interventions which reduce system reaction to environmental stressors and maintain system stability in response to stressors. Tertiary prevention includes interventions which restore system stability following the impact of stressors.

For the purpose of this study, the client system is the family caregiver of a demented nursing home resident. The burden of caring for a demented family member requires energy; therefore, caregiver burden is a stressor which threatens system stability. Caregiver burden is both objective and subjective and may be a stressor from the internal, external, and/or created environments. Family caregivers vary in the amount of energy available to respond to the burden of caring for a demented relative. Factors which may influence the amount of energy available to the family caregiver include, but are not limited to, economic resources, functional status of the caregiver, and knowledge of healthcare practices. Care-recipient variables which may increase the intensity of caregiver burden and, therefore, consume significant energy may include physical dependency or improper social functioning commonly associated with dementia (Bull, 1990; Given, Collins, & Given, 1988; Given et al., 1988; Haley & Pardo, 1989).

Primary prevention as intervention for caregiver burden among family caregivers of relatives with dementia outside of the nursing home setting which may strengthen the flexible line of defense and optimize wellness in the family caregiver system includes family counseling or caregiver support groups. Secondary prevention as intervention that may reduce the impact of caregiver burden so that system stability is maintained includes visiting nurse or respite services. When the stress of caring for a demented relative outside of the nursing home depletes energy to the extent that the family caregiver's normal line of defense is penetrated in spite of secondary intervention, a need for nursing home care exists. Tertiary prevention as intervention for caregiver burden among family caregivers of relatives with dementia includes nursing home care for the demented relative. Satisfactory nursing home care strengthens the lines of resistance because caregiving activities are performed by nursing home staff, conserving energy within the family caregiver system

Many stressors, known or unknown, may consume energy and threaten system stability of the family caregiver of the demented nursing home resident. Two dimensions of caregiver reactions, impact on schedule or lack of caregiver esteem, are stressors which effect stability of the family caregiver system following nursing home placement of a demented family member (Figure 2).

Family caregiver satisfaction with nursing home care is a system variable which strengthens the lines of resistance so that the core of the family caregiver system is protected and stability may be restored to the system following nursing home placement of a demented relative. Dissatisfaction with nursing home care may be an additional stressor upon the family caregiver system resulting in further instability in the system. Nursing home placement as a tertiary intervention for caregiver burden may not restore the family caregiver system to the level of the flexible line of defense because other stressors may consume energy. Nevertheless, family caregiver satisfaction with nursing home care may resist caregiver burden so that the core of the family caregiver system is protected. Further interventions, such as family counseling, may restore the normal line of defense.

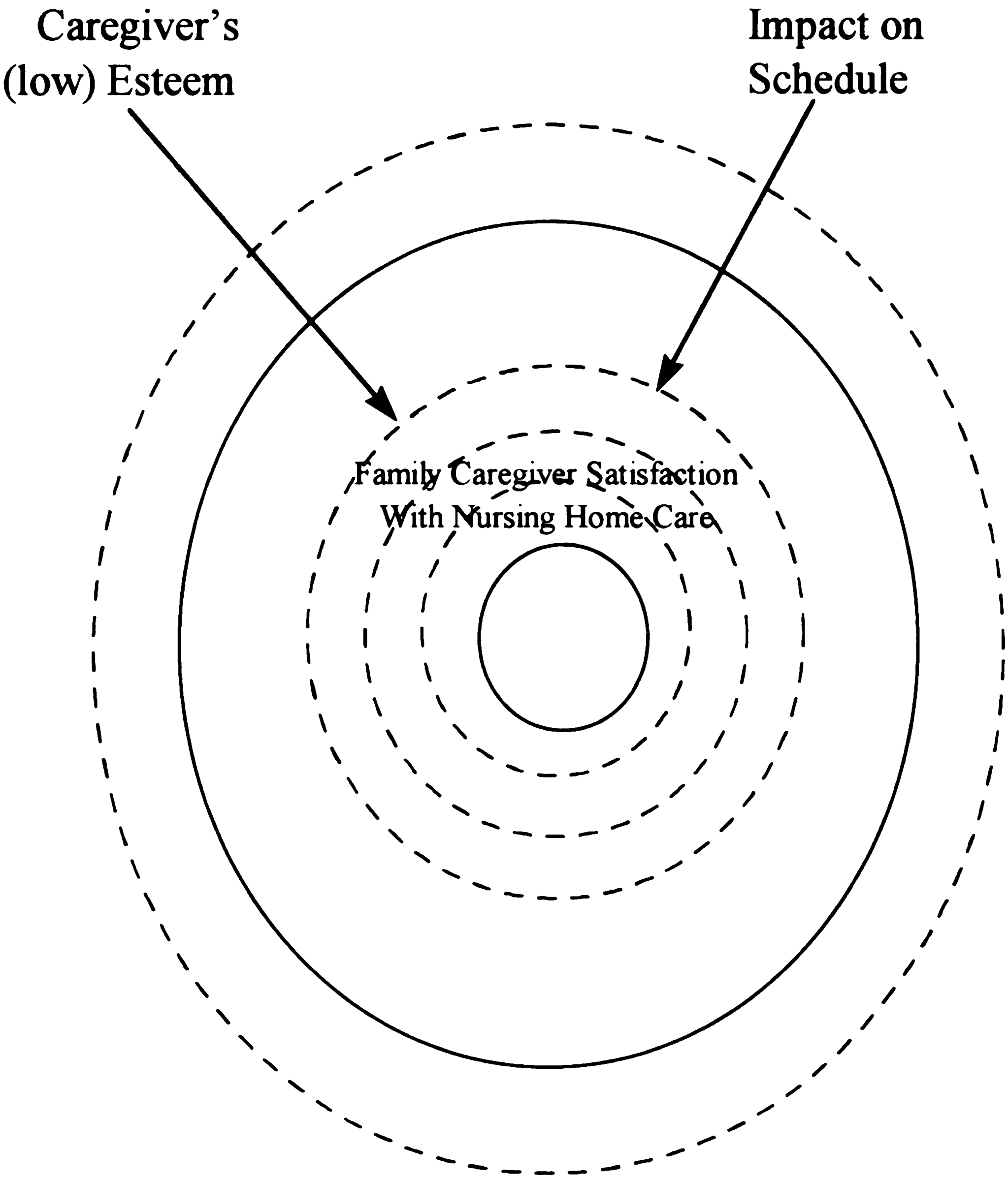

Figure 2 Family Caregiver Satisfaction With Nursing Home Care Related to Two Dimensions of Caregiver Burden

Chapter IV

METHODS

The current study utilized pre-existing data from a larger research project entitled, "The Impact of Alzheimers Disease on Family Caregivers" (NIMH #2 RO1 41766, Clare Collins, R.N., Ph.D., F.A.A.N., principle investigator). The study was funded by the National Institute of Mental Health and carried out by the College of Nursing at Michigan State University from 1989 to 1993. A longitudinal survey design was used with three measurement points during the four year period of data collection. At each data collection point, family caregivers participated in a one and one-half hour telephone interview and completed a mailed self-administered booklet. One of the many objectives of the larger study was to describe family caregiver reactions to the caregiver role following institutionalization of their family member. Family caregivers who experienced nursing home placement of their relative continued to participate in the larger study.

In the larger study, a convenience sample of 350 family caregivers was recruited through mailings to potential participants located through the

Alzheimers Association and other healthcare agencies in southwestern Michigan. Caregiver/care-recipient dyads who met the following criteria were enrolled in the study: (1) the caregiver was self-identified as the family member providing the most care to a relative with Alzheimers Disease or related dementia; (2) the care-recipient was at least 55 years of age and dependent in at least one ADL, such as need for assistance with bathing, dressing, or feeding, and one instrumental ADL, such as need for assistance with grocery shopping, preparing meals, or managing finances; (3) the care-recipient had received a diagnosis of Alzheimers Disease or related disorder (by caregiver report; no independent confirmation of diagnosis was made); and (4) the caregiver and care-recipient resided outside of an institution at the time of entry into the study. Caregivers from the larger study who subsequently institutionalized their relative following enrollment in the larger study compose the sample for the current study (N = 97).

Consent procedures for the original study conformed to the guidelines of the Department of Health and Human Services and were approved by Michigan State University's Committee for Research Involving Human Subjects (UCRIHS). Procedures consisted of a verbal explanation of the study by the interviewer at the screening interview, completion of a written consent form at the first interview, and explanation followed by verbal reaffirmation of consent at each subsequent telephone interview. Additional approval from Michigan State University's UCRIHS was obtained prior to data analysis for the current study (Appendix A).

Measurement of Family Caregiver Burden

Two subscales of the CRA (Given, et al., 1992), Caregiver Esteem and Impact on Schedule, were used to measure caregiver burden in this study. The CRA is administered in a 5-point Likert questionnaire format, with responses ranging from, (1) strongly disagree, to (5) strongly agree. Items on the Caregiver Esteem and Impact on Schedule subscales are positively coded with the exception of one item on the Caregiver Esteem subscale, "I resent having to care for ___," which is coded in a negative direction. A lower score on the Caregiver Esteem subscale or a higher score on the Impact on Schedule subscale represents greater burden. The CRA is intended to be used to study family caregivers of disabled, dependent, or ill older adults, regardless of the diagnoses of the care recipient, familial relationship of the caregiver to the care recipient, the setting in which care is given, or healthcare agencies involved. The CRA was published in 1992 (Given, et al.) and has been used extensively to study family caregiving. Nevertheless, prior to the present study, the CRA has not been used to analyze reactions of family caregivers with relatives in a nursing home.

An adequate sample (N = 754) of caregivers, was studied in the development of the CRA. During the exploratory phase of the CRA's development 377 family caregivers of elderly patients were studied; 267 were caregivers of family members with physical impairments, and 110 were caregivers of family members with dementia. 185 cases from the exploratory sample were compared longitudinally at six-month intervals in three waves. During the confirmatory phase of the CRA's development, 377 different caregivers were studied; 276 were caregivers of family members who had cancer and 101 were caregivers of family members with dementia.

Several methods for assuring the validity of the CRA were demonstrated during the CRA's development. Initially, each member of a team of five researchers from the College of Nursing at Michigan State University agreed on the face validity of any item that was considered relative to a dimension of the CRA. Construct validity of the CRA was further established by correlating caregiver depression and the number of care-recipient ADL dependencies with the five subscales of the CRA. Final evidence of construct validity included the stability of factor structures across comparison groups of caregivers and measurement occasions during three waves of longitudinal analysis.

Reliability of the five subscales of the CRA is demonstrated by internal consistency; Cronbach's Alpha ranged from .80 to .90 for the five subscales and mean inter-item correlation's range from .47 to .60 (Given et al., 1992) for each of the five subscales. Items that compose the Caregiver Esteem and Impact on Schedule subscales of the CRA are listed in Appendix B. Cronbach's alpha for the Caregiver Esteem and Impact on Schedule subscales respectively was .90 and .82, and the mean inter-item correlation's for the Caregiver Esteem and Impact on Schedule subscales were .56 and .47 respectively. The interscale correlation between Caregiver Esteem and Impact on Schedule subscales of the CRA was -.179 (2 tailed $p < .01$) which is a low correlation and supports the notion that these subscales represent two distinct dimensions of caregiver reactions (Given et al., 1992).

Measurement of Family Caregiver Satisfaction with Nursing Home Care

Family caregiver satisfaction with nursing home care was measured using an unpublished instrument that was developed by researchers at the College of Nursing, Michigan State University. The instrument was developed for use in a study entitled, "Impact of Alzheimer's Disease on Family Caregivers," that was funded by grants from the National Institute of Mental Health, NIMH #1 R01 41766 and NIMH #2 R01 41766, awarded to C. W. Givin, M.D. and Clare Collins, Ph.D., R.N., F.A.A.N., principal investigators respectively. The purpose of the study was to examine how caregiver responses, involvement in care, and need for and use of community-based and institutional services changed with the progression of their relative's disease. In addition, caregiver reactions to institutionalization were examined.

Items for the nursing home satisfaction instrument were generated from five focus groups of family members who cared for relatives with dementia, some of whom had been placed in a nursing home (n = 79). The purpose of the groups, utilizing a qualitative approach, was to develop instruments to measure aspects of community and institutional service use. Interactions during the focus groups, the duration of which was two hours each, were audio-recorded and transcribed. The transcription was reviewed to extract potential items for measuring family caregiver satisfaction with nursing home care. Researchers from the College of Nursing at Michigan State University critically reviewed published literature relative to family caregiver satisfaction with nursing home care, which is sparse, to assure validity of items generated from the focus groups. Items that were proposed to measure family caregiver satisfaction with nursing home care were formatted and pilot tested before inclusion in an instrument that could be used to measure family caregiver satisfaction with nursing home care.

Initially, eighteen items relevant to family caregiver satisfaction with nursing home care were generated from the focus groups. Exploratory factor analysis, using an oblique rotation, identified four factors. Items that loaded on one factor at a level of greater than .50 and loaded on other factors at less than .30 were retained. Seven items were eliminated and two subscales were identified. No confirmatory factor analysis was performed. Experts on family caregiving from the College of Nursing at Michigan State University reviewed the items on the final subscales for face validity. One item, measuring nursing home cost, was eliminated based on lack of similarity with other items on that subscale. Items that composed these two subscales of nursing home satisfaction resemble Bower's (1988) preservative care and technical care and are listed in Appendix C.

Subscales of family caregiver satisfaction with nursing home care, preservative and technical care, contain seven and four items respectively. Responses to the family caregiver satisfaction with nursing home care subscales are coded on a 4-point Likert type questionnaire with responses ranging from (1) very dissatisfied to (4) very satisfied; all positively coded. A high score on either subscale represents a high level of satisfaction. Cronbach's alpha for preservative and technical subscales of family caregiver satisfaction with nursing home care were .90 and .86 respectively, and mean inter-item correlation's are .62 and .61 respectively, which demonstrates a high level of reliability. The interscale correlation for the two subscales is .59, providing some support that these scales may represent two dimensions of family caregiver satisfaction with nursing home care.

CHAPTER V

RESULTS

Description of the sample

Sociodemographic characteristics of family caregivers and their institutionalized relatives are listed in Table 1. This was a small (N = 97), homogenous, convenience sample, consisting predominantly of white, well educated caregivers. The majority of the caregivers in the sample was female (60%), but many in the sample were male (40%). Spouse caregivers were in the majority (62%). Nonspouse family caregivers included children (26%) and children-in-law (12%). The sample was variable relative to the age of the caregiver (30-88 years) and the age of the institutionalized adult (58-92 years). Most of the caregivers were married (90%) which is not surprising given the majority of spouse caregivers. Institutionalized relatives of family caregivers in the sample had resided in the nursing home for an average of 12 months, ranging from 1 to 24 months.

Table 1. Sociodemographic Characteristics of Family Caregivers and Institutionalized Adults with Dementia

	Caregivers (N= 97)	**Institutionalized Adults (N = 97)**
Gender		
Male	27	39
Female	70	58
Family Relationship of Caregiver to Patient		
Spouse	60	
Child	25	
Child-in-Law	12	
Marital Status		
Single	3	0
Married	87	63
Widowed	4	33
Divorced	3	1
Age (one caregiver and one care recipient missing)		
Mean	64	75
Standard Deviation	7.1	6.5
Range	30-88	58-92
Race		
White	95	95
Black	2	2
Education (one care recipient missing)		
Grade School	5	14
Some High School	6	17
High School	29	27
Some College	30	15
College Graduate	14	18
Professional/Grad School	13	5
Number of Months in Institution (one care recipient missing)		
Mean		12
Standard Deviation		6.2
Range		1-24

Interscale Correlation's and Item Means

The interscale correlation between Caregiver Esteem and Impact on Schedule was .07 which is lower than that reported in the literature and clearly suggests that these subscales are measuring two distinct dimensions of caregiver reactions. The interscale correlation between Satisfaction with Preservative Nursing Home Care and Satisfaction with Technical Nursing Home Care was .59 which is consistent with the correlation when the scales were developed and supports the notion that these subscales may represent two distinct dimensions of family caregiver satisfaction with nursing home care.

Mean scores and standard deviations on subscales of caregiver reactions and satisfaction with nursing home care among family caregivers of institutionalized adults with dementia are listed in Table 2. Caregiver reactions were measured on a 5-point Likert scale with responses ranging from strongly agree to strongly disagree. A lower score on the Caregiver Esteem subscale or a higher score on the Impact on Schedule subscale represented greater caregiver burden. The two dimensions of family caregiver satisfaction with nursing home care was measured on a 4-point Likert scale with responses ranging from very dissatisfied to very satisfied. A higher score on either satisfaction subscale, Preservative or Technical, represented greater family caregiver satisfaction with nursing home care of a demented relative. Mean burden scores [Caregiver Esteem (M =3.59, SD = .61); Impact on Schedule (M = 3.00, SD = .76)] were moderately high, with limited variability around the mean. Mean satisfaction scores [Satisfaction with Preservative Care (M = 3.40, SD = .61) and Satisfaction with Technical Care (M = 3.50, SD = .58)] in this study were high, also with limited variability around the mean.

Table 2. Mean Scores on Subscales of Caregiver Reactions and Satisfaction with Nursing Home Care among Family Caregivers of Institutionalized Adults with Dementia

	Mean	Standard Deviation (Range)
Caregiver Reactions		
Caregiver Esteem (N = 94)	3.59	.61 (2.00-5.00)
Impact on Schedule (N = 94)	3.00	.76 (1.00-4.80)
Satisfaction with Nursing Home Care		
Satisfaction With Preservative Care (N = 94)	3.40	.61 (1.29-4.00)
Satisfaction With Technical Care (N = 93)	3.50	.58 (1.00-4.00)

NOTE:
Possible scores for caregiver reactions range from (1), strongly disagree to (5), strongly agree.
Possible scores for nursing home satisfaction range from (1), very dissatisfied to (4), very satisfied

Results of Hypothesis Testing

Correlation's between subscales of caregiver reactions and satisfaction with nursing home care among family caregivers of institutionalized adults with dementia are listed in Table 3. It was hypothesized that family caregiver satisfaction with preservative nursing home care would be positively correlated with caregiver esteem. This hypothesis was supported (r = .23; two tailed p = .03; df 93). It was hypothesized that family caregiver satisfaction with preservative nursing home care would be negatively correlated with caregiver impact on schedule. Although the correlation was in the predicted direction, it failed to reach statistical significance and did not support the hypothesis (r = -.13, two tailed p = .20, df 93).

Table 3. Correlation's Between Subscales of Caregiver Reactions and Satisfaction withNursing Home Care among Family Caregivers of Institutionalized Adults with Dementia

	Caregiver Esteem (_N_ = 94)	Impact on Schedule (_N_ = 94)
Satisfaction with Preservative Care	.23*	-.13
Satisfaction with Technical Care	.10	-.25*

*p < .05, 2-tailed

It was hypothesized that family caregiver satisfaction with technical nursing home care would be positively correlated with caregiver esteem. This hypothesis was not supported (r = .10, two tailed p = .32, df 93). It was hypothesized that family caregiver satisfaction with technical nursing home care would be negatively correlated with caregiver impact on schedule. This hypothesis was supported (r = -.25; two tailed p =.02; df 93).

The literature often reports family caregiving among various caregiver groups, such as spouses, adult children, or daughters (Brackley, 1992; Brody, 1985; Corcoran, 1993; Green, 1991; King et al., 1993; Matthiesen, 1989; Pruchno et al., 1990; Ross et al., 1993; Smith & Bengston, 1979; Temple & Fawdry, 1992). Therefore, additional analyses for this study included separating the sample by spouse (N = 57) and nonspouse (N = 36) caregivers and examining the hypotheses for each subgroup. The results of these analyses are presented in Table 4.

Table 4. Correlation's between Subscales of Caregiver Reactions and Satisfaction with Nursing Home Care Among Spouse and Nonspouse Caregivers of Institutionalized Adults with Dementia

	Caregiver Esteem		Impact on Schedule	
	Spouse (n = 57)	Nonspouse (n = 36)	Spouse (n = 57)	Nonspouse (n = 36)
Satisfaction with Preservative Care	.38**	-.01	-.16	-.25
Satisfaction with Technical Care	.24	-.12	-.28*	-.33*

*p < .05, 2-tailed
**p < .01, 2-tailed

Among spouse caregivers, caregiver esteem was significantly correlated with satisfaction with preservative nursing home care (r = .38, two tailed p = .003; df 57) but not significantly correlated with satisfaction with technical nursing home care (r = .24; two tailed p = .07; df 56). Impact on schedule was negatively correlated with satisfaction with technical nursing home care among both spouse (r = -.28; two tailed p = .03; df 56) and nonspouse caregivers (r = -.33; two tailed p = .049; df 35). Impact on schedule was negatively, but not significantly, correlated with satisfactory preservative nursing home care among both spouse (r = -.16; two tailed p = .22; df 57) and nonspouse caregivers (r = -.25; two tailed p = .13; df 35).

Generally, when comparing subgroups of family caregivers, spouse and nonspouse, the magnitude of the correlations increased among spouse caregivers, especially the relationship between caregiver esteem and satisfaction with preservative nursing home care. When separating the sample into subgroups for analysis, the correlation between satisfaction with preservative care and caregiver esteem became insignificant among nonspouse caregivers. The magnitude of the correlation between impact on schedule and satisfaction with technical care increased among spouse and nonspouse caregivers compared to caregivers in general.

Discussion

The sample in this study was small, nonrandom, and homogenous, consisting of predominantly white, well educated family caregivers, and may not be representative of the general population of family caregivers of nursing home residents with dementia. Many in the sample were spouse caregivers, which may not represent the general population of family caregivers of institutionalized adults with dementia. It may be that a large number of spouses was represented in this sample due to greater emotional attachment to the care recipient and greater perceived caregiver responsibility among spouses, versus other caregiver subgroups. Subsequently, spouses may have been more interested in participating in a study that might validate their caregiving experience and be helpful to other family caregivers in the future. Furthermore, spouses, who may be relieved of child rearing responsibilities and retired from active employment, may have more time to participate in a caregiver study.

Nonspouse caregivers, including children and children-in-law who, the literature suggests, represent a large number of family caregivers in the nursing home setting, were a minority in this sample. Adult children with careers and families may have declined to participate in this study due to conflicting demands on their time. Therefore, the results of this sample cannot be used to make inferences about the general population of family caregivers, particularly adult children, of nursing home residents with dementia.

In addition to homogeneity in terms of familial relationship, marital status, race, and education, the sample was also homogenous in response to the study variables, resulting in lack of variability around the mean. Lack of variability in responses may explain the relatively low correlations observed in this study. More variability in response to subscales of caregiver burden or satisfaction with nursing home care may have increased the strength of the correlations between subscales.

In this study, care recipients had been institutionalized from one to twenty-four months (M = 12; SD = 6.2). The number of family caregivers in the sample whose relative with dementia had resided at the nursing home for a relatively short time, such as less than one or two months, is unknown. Initial days, weeks, and months following nursing home placement of a family member with dementia may be considerably stressful for the family caregiver. During this initial phase, family members are becoming acclimated to the nursing home setting, and family dynamics are interfacing with institutional dynamics. It may be that caregiver burden and/or satisfaction with nursing home care during the first month following institutionalization are different from the general experiences of family caregivers. Measures of family caregiver satisfaction and family caregiver burden during the initial phase following nursing home placement of a relative with dementia may skew the data and fail to represent the general reactions of family caregivers of nursing home residents with dementia.

The care needs of the nursing home residents in this sample are also unknown. The needs of nursing home residents with dementia may vary considerably. Some may need minimal supervision; some may need partial assistance with ADL's, others may be uncooperative or combative; others may need complete care for ADL performance. Some nursing home residents with dementia may be "pleasantly confused;" others may be moody and angry; others may be in a vegetative state. The variable nature of mental and physical problems associated with dementia may effect measures of caregiver burden and satisfaction with nursing home care among family caregivers of institutionalized adults.

This study was limited to the design of the larger study in which there were few controls and no manipulation of variables; therefore, causation cannot be inferred. The data were self-reported and dependent upon the subjective experience of family caregivers. Nevertheless, limitations in the design of the larger study are understandable given the nature of the variables and ethical considerations that limit the application of control measures in scientific investigation of family caregiving.

Additional limitations of the current study include the fact that measurement instruments of caregiver burden and satisfaction with nursing home care have questionable validity. Although the CRA is recommended for use in varied circumstances of family caregiving, the CRA has not previously been used in the nursing home setting. The two subscales measuring family caregiver satisfaction with nursing home care may not reflect Bower's description of preservative and technical care. For example, some items on the preservative subscale, such as "Number of staff available to your relative," or "Skill and ability of staff caring for your relative" seem to be somewhat technical in nature. Furthermore, items on the technical subscale, such as "How frequently your relative is seen by a doctor," seem to focus on medical care and does not include many other aspects of technical care such as nursing care to prevent pressure ulcers.

The mean interscale correlation between the two subscales for measuring family caregiver satisfaction with nursing home care (.59) does not provide strong evidence that these subscales represent two distinct dimensions of satisfaction. The measurement instrument for family caregiver satisfaction with nursing home care has not undergone confirmatory analysis. Thus there are several concerns about the measurement instruments in this study, both conceptually and operationally. Nevertheless, limitations relative to measurement instruments are understandable given that additional measures of burden or satisfaction in the nursing home setting are not available.

Existing literature relative to family caregiving in the nursing home setting is sparse. King, et al. (1991) compared family caregiver reactions pre- and post-institutionalization and found that family caregivers of frail elders (not elders with dementia) experience impact on schedule (M = 3.4; SD = .94; df 35) following institutionalization. This finding supports the results of the current study relative to impact on schedule of family caregivers of nursing home residents. This researcher found no references in the literature relating caregiver esteem or impact on schedule with nursing home satisfaction among family caregivers of demented nursing home residents.

The results of this study may mean that satisfaction with preservative nursing home care among family caregivers of demented nursing home residents is related to increased caregiver esteem, which was the hypothesis of the study. Nevertheless, it is entirely possible that family caregivers who have low caregiver esteem also have low self-esteem in general. Caregivers with generally low self-esteem may be dissatisfied with many things in life, including the nursing home care of their family member. Thus, it may be that low self esteem is associated with general dissatisfaction in life, which limits the implications of the current study. Furthermore, many other variables, such as self efficacy, hardiness, or access to the healthcare system, are likely to affect both nursing home satisfaction and caregiver esteem.

Caregiver esteem may be unrelated to satisfaction with technical care because the family caregiver expects the nursing home staff to be responsible for technical care, whereas the family caregiver retains a sense of responsibility for preservative care. When caregiver esteem is correlated with satisfactory preservative care and separated by spouse and nonspouse caregivers, the relationship became insignificant among nonspouse caregivers and increased in significance among spouse caregivers. It is likely that the intimacy of the spousal relationship, compared to the nonspouse, may have led the spouse caregivers to feel more responsible for preservative care than technical care.

Furthermore, it is possible that the spouse, probably of an older generation than the nonspouse, may continue to hold a paternalistic view of the healthcare system. This paternalistic view, which was common in an earlier era of healthcare and continues to influence today's healthcare consumers, expected the healthcare consumer to accept healthcare services unquestioningly, not to evaluate the adequacy or appropriateness of healthcare practices and not to actively participate in healthcare decisions.

Thus, it may be that caregivers in this study lacked a vision for satisfactory technical nursing home care.

A competing explanation for caregiver esteem having been significantly correlated with family caregiver satisfaction with preservative care but not related to satisfaction with technical care is the possibility that nursing homes in this study were consistently providing a high level of technical care; thus technical care was a "non-issue," leaving family caregivers to focus on preservative care. This explanation lacks support from the literature which suggests that many family caregivers are not satisfied with nursing home care (Collins, et al., 1994) and preservative care is an important element of technical care (Bowers, 1988).

The results of this study suggest that satisfaction with technical aspects of nursing home care among family caregivers of demented nursing home residents is related to lower levels of impact on schedule among both spouse and nonspouse caregivers. Family caregivers who were not satisfied with technical aspects of nursing home care may fear for the safety and physical well-being of their relative. These caregivers may visit the nursing home more frequently and stay longer to oversee and supplement the hands-on care expected from nursing home caregivers. Time spent traveling to the nursing home and assisting with the physical care of a demented relative is likely to take away from the family caregiver's personal activities and impact on their schedule. A competing explanation is that caregivers who generally have difficulty managing their time may experience greater perceived impact on schedule and be dissatisfied with various aspects of life, including nursing home care of their relative with dementia.

Lack of a significant relationship between impact on schedule and family caregiver satisfaction with preservative care may be explained by the fact that preservative care probably can be provided on a more flexible time schedule over a longer period of time, whereas technical care must be performed regularly throughout the day on a more rigid schedule. For example, looking at a family photograph album (preservative care) may be therapeutic at any time of the day, once or twice a week, but bathing, positioning, and feeding (technical care) probably needs to be provided every 2-4 hours throughout the day and night. A family caregiver who attempts to compensate for perceived unsatisfactory technical nursing home care by overseeing or personally supplementing care may find that the rigid time demands of technical care has a significant impact on schedule.

In summary, satisfaction with preservative nursing home care is significantly related in a positive direction to caregiver esteem among spouse caregivers of nursing home residents with dementia. Satisfaction with preservative nursing home care is unrelated to caregiver esteem among nonspouse caregivers of nursing home residents with dementia. Satisfaction with preservative nursing home care is unrelated to impact on schedule among both spouse and nonspouse caregivers of nursing home residents with dementia. Satisfaction with technical nursing home care is unrelated to caregiver esteem among both spouse and nonspouse caregivers of nursing home residents with dementia. Satisfaction with technical nursing home care is significantly related in a negative direction to impact on schedule among both spouse and nonspouse caregivers of nursing home residents with dementia.

Implications for Practice

Due to limitations in the sample and design of this study, implications for practice must be considered cautiously. Inferences cannot be made relative to causation between family caregiver burden among family caregivers of nursing home residents and satisfaction with nursing home care. Significant investment of healthcare dollars or changes in nursing home policies and procedures are not reasonable based on this study. Nevertheless, according to the framework of Stetler & Marram (1976) this study may be used to enhance the understanding of family caregiving in a nursing home setting, and the nurse may consider the findings for possible future use. For example, a nurse in the nursing home who observes evidence of caregiver burden among family caregivers may want to consider an assessment of the family caregiver's satisfaction with nursing home care. Conversely, a nurse in the nursing home who is dealing with a dissatisfied family caregiver may want to assess the family caregiver's perception of burden.

Based on the results of this study, which reports that a large portion of the sample was satisfied with nursing home care, primary care providers need not refrain from recommending nursing home placement of a demented relative to a burdened family caregiver. Nevertheless, the primary care provider may caution the family that caregiver burden may persist following nursing home placement. Primary care providers may counsel family caregivers to compare nursing homes for evidence of satisfactory care prior to selecting a nursing home.

Based on these results, which suggest that family caregivers of nursing home residents experience lack of caregiver esteem and impact on schedule, nurses in a nursing home may be encouraged to view nursing home care from a family centered perspective. A family centered approach to care suggests that nurses may assess the family caregiver system, especially the spouse caregiver, identify problems, and create approaches to help family members of nursing home residents.

Nursing home caregivers should abide by requests from families to preserve the individuality and dignity of nursing home residents by decorating the room with familiar objects, such as family photographs, and accommodating past patterns, such as distinct food preferences, sleep schedules, activity preferences, religious customs, etc. Nursing homes should attempt to avoid rigid rules which can be barriers to preservative caregiving in the nursing home. The family caregiver should be encouraged to participate in decision making regarding the plans for care for their relative with dementia.

Suggestions for Further Research

Further research is needed to develop valid and reliable tools for studying family caregiving in the nursing home. Representative samples of family caregivers of nursing home residents are needed to make valid inferences relative to family caregiving in the nursing home setting. Further research with a larger, more heterogeneous sample is recommended. Research comparing caregiver subgroups, particularly spouse caregivers versus other family caregivers, is suggested considering the significant burdens impacting the spouse caregiver in the nursing home setting. Analysis of specific subgroups of caregivers, such as male, female, employed, and unemployed caregivers, may also be useful. Further research using samples of family caregivers of nursing home residents with disease processes other than dementia, such as heart disease, arthritis, or depression, may be useful to provide further insight relative to family caregiver burden and satisfaction with nursing home care. It may be that family caregiver burden among family caregivers of nursing home residents in general, not just among family caregivers of nursing home residents with dementia, is related to satisfaction with nursing home care.

Longitudinal studies examining burden before nursing home placement and level of satisfaction following placement may be useful to control for variations in burden. Researchers may want to study family caregivers during the first month following nursing home placement to capture unique variables during the initial phase of nursing home adjustment. Other researchers may want to eliminate family caregivers from the initial phase following nursing home placement of a relative when making inferences about family caregivers of nursing home residents in general. Further research is recommended which focuses on family caregivers of nursing home residents who show evidence of low caregiver burden and high satisfaction with nursing home care to identify relevant variables and elicit possible intervention strategies for family caregivers experiencing burden in the nursing home setting.

Family caregiver satisfaction with nursing home care may be studied as an outcome criteria to assess the quality of nursing home care for nursing home residents with dementia. Assessment of family caregiver satisfaction with nursing home care may be a cost-effective way to assess nursing home quality, supplementing government oversight.

Evaluation of Theoretical Framework

Neuman's Systems Model was appropriate for this study considering the lack of specific frameworks for family caregiving in the nursing home. Although the Neuman Model is broad, it provided some guidance for understanding relationships among the variables in this study. Significant results relating caregiver esteem with satisfactory preservative care and relating impact on schedule with satisfactory technical care support Neuman's concepts of stressors and their relationship to system stability. Mixed results from this study are understandable in view of the framework upon which this study is based which assumes that complex elements within the family caregiver system and the environment are interacting. Thus, in addition to lack of caregiver esteem or impact on schedule, many variables, known and unknown, may be consuming energy and threatening system stability in the family caregiver system of the demented nursing home resident.

Theories of family caregiving that describe, explain, and predict experiences of the family caregiver and generate possible intervention strategies for family caregiver burden need to be developed. Family caregiving theory needs to be developed to a level that includes family caregiving for relatives with dementia among various groups of caregivers in various environments, including the nursing home.

Conclusion

Aging in our society is characterized by undesirable transitions, such as changing physical appearance, decreasing physical stamina, onset of chronic health problems, declining economic resources, or death of family members and friends. An aging person with dementia may lose essential qualities that define a person as part of the larger human family, such as loss of the ability care for oneself or to communicate with loved ones. Family caregivers of aging adults with dementia provide a valuable service to society in that they provide much of the care for their relatives, even after nursing home placement. Unfortunately, family caregivers experience significant burden associated with caregiving, and their burden persists after nursing home placement.

A negative stereotype is associated with nursing homes in our society. Nursing homes have roots in nineteenth century poorhouses and early twentieth century state mental hospitals which may explain some of the social stigma attached to nursing homes. Unfortunately, present-day nursing homes have been modeled after acute-care hospitals with the focus on curing illness. Thus, nursing homes are limited in their ability to create a therapeutic milieu designed to meet the complex psychosocial needs of residents with dementia (Collopy, Boyle, & Jennings, 1991). Generally, nursing homes house elderly women in a society that undervalues both women and the elderly, which may explain some of the negative feelings towards nursing homes. Media hype associated with reporting nursing home outcomes in terms of the "worst-case scenario" serves to perpetuate the negative stereotype of nursing homes. The stigma associated with nursing homes is reinforced by the myth that family caregivers abandon demented relatives following nursing home placement.

Perpetuating negative views of nursing homes may be a defensive coping strategy which protects society from acknowledging that a person may lose basic human qualities as the result of illness. Society may prefer to deny the potentially morbid implications of a dementing illness, thus blaming nursing homes and/or family caregivers for the consequences of dementia. Unfortunately, society's negative view of nursing homes adds to the already significant burden of family caregivers of relatives with dementia who need nursing home care.

Substandard, negligent, and abusive treatment may occur in nursing homes, but nursing homes are not totally to blame. Health care personnel, including nursing home workers, generally have a desire to do good. Caring for demented nursing home residents is a formidable task, and society has not provided nursing homes with the necessary tools to provide quality nursing home care for residents with dementia. A unified paradigm for nursing homes that guides effective care for residents with dementia is not supported by a research-based body of knowledge. Thus, family caregivers of nursing home residents, nursing home professionals, and government regulators may have disparate definitions of nursing home care without a firm vision for quality in nursing homes.

Barring the unlikely possibility that nursing homes will become unnecessary and obsolete in the future, politicians and regulatory agencies must work with family caregivers, nursing home professionals, and researchers to formulate an integrated and consistent view for the role of nursing homes in our society. Political rhetoric will not improve the conditions in nursing homes, and government over-regulation may be a barrier to quality nursing home care. Achieving a common view of the "good" nursing home is a challenging goal that cannot be achieved without further research. Family caregiver satisfaction with nursing home care may be a valid and cost effective measure of quality nursing home care for residents with dementia.

APPENDICES

APPENDIX A

Letter of Approval from Michigan State University's Committee for Research Involving Human Subjects

MICHIGAN STATE
UNIVERSITY

May 24, 1995

TO: Clare Collins
A-129 Life Sciences

RE: IRB#: 95-273
TITLE: SATISFACTION WITH NURSING HOME CARE RELATED TO CAREGIVER BURDEN AMONG FAMILY CAREGIVERS OF INSTITUTIONALIZED ADULTS WITH DEMENTIA
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 05/24/95

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 and any revision listed above.

RENEWAL: 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 use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. 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.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:kaa/lcp

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

niversity Committee on
Research Involving
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APPENDIX B

Subscale Items for Two Dimensions of Family Caregiver Burden: Caregiver Esteem and Impact on Schedule*

Caregiver Esteem

1. I feel privileged to care for _____.
2. I really want to care for _____.
3. I enjoy caring for _____.
4. Caring for _____ makes me feel good.
5. Caring for _____ is important to me.
6. I will never be able to do enough to repay _____.
7. I resent having to care for _____ (reverse scored)

Impact on Schedule

1. My activities are centered around care for _______.
2. I have stopped in the middle of my work or activities to provide care.
3. I have eliminated things from my schedule since caring for _____.
4. The constant interruptions make it difficult to find time to care for______.
5. I visit family and friends less since I have been caring for _____.

*Possible responses range from, (1) strongly disagree to, (5) strongly agree. A lower score on the caregiver esteem subscale and a higher score on the impact on schedule subscale represents greater burden. All items, except one, are positively scored.

APPENDIX C

Subscale Items for Two Dimensions of Family Caregiver Satisfaction With Nursing Home Care*

Preservative Care

1. Quality of food your relative receives.
2. Number of staff available to your relative.
3. Skill and ability of staff caring for your relative.
4. Attitudes of persons caring for your relative
5. Degree of respect and dignity shown to your relative
6. Ability of staff to care for someone with Alzheimer's.
7. Staff willingness to listen and act on your concerns

Technical Care

1. Measures taken by staff to provide safety for your relative.
2. Medical care provided for your relative.
3. How frequently your relative is seen by a doctor.
4. Medications given to your relative for treatment of illness.

*Possible responses range from, (1) very dissatisfied to, (4) very satisfied. A higher score represents greater satisfaction. All items are positively scored.

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