# Stress on caregivers of the elderly

This article considers the health threats to a vulnerable population, caregivers of the frail elderly who are maintained in the community. A model of competing care demands is derived from Orem's self-care theory and from caregiver literature to propose that the caregiver, when faced with dwindling resources of energy, time, and money, is forced to choose between self-care and dependent care of the elder. Often, the individual neglects his or her own health to continue to give care. The suggested research projects presented here assess those nursing interventions that complement and support caregiving.

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CARING FOR A disabled loved one is an important part of many people's lives. This care may range from temporary support after an acute incident to a commitment of major amounts of resources lasting for many years. The effects on caregivers can be profound and irreversible. Their social and family relationships will be affected as well as their careers and all the routines of daily life. There is probably no aspect of living that will not be influenced in some way by the experience of this role if it becomes a major focus of the caregiver. This group of caregivers is growing as technological advances help the elderly and other vulnerable populations live more years of essentially dependent existence.

Nurses planning the care of the elderly in the community recognize that the health of the person caring for the elderly client may be at risk because of the many demands placed on the resources of that individual. This article describes the characteristics

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and expectations of caregivers and their abilities to care for themselves and dependent elders.

In Orem's General Model of Self-Care the "complex capability for action that is activated in the performance of the actions or operations of self-care" is called self-care agency.[1(p31)] For the person caring for a disabled elder this complex capability must be activated for the performance of care of the dependent elder as well as for care of the self. It is proposed that the caregiver must make a choice between the needs of the self and those of a dependent elder, and that the caregiver often neglects his or her own health to care for the older relative or loved one.

## THE FRAIL OR IMPAIRED ELDERLY

America is growing older. The ratio of the population over the age of 65 is now 12% compared to only 4% in 1900, and it is estimated that by the year 2030 one in five Americans will be in this age group.[2] Of even more interest to nurses are the projected increases in the over-85 age group, who tend to have added impairment and disability.[3]

Older Americans will present a challenge to public policy and professionals to provide support for them to maintain their health and quality of life in a time of changing social and economic conditions.[4] At present, the responsibility for providing care for the increasing numbers of elderly has fallen primarily on their families.[5,6]

A survey conducted by the Health Care Financing Agency in 1982 found that there were 5 million functionally impaired elderly in the United States being maintained in the community. This constitutes 19% of total Medicare enrollment.[3]

There are benefits to the individuals and to society in general for the impaired elderly to be maintained in the home setting. First, continuing to play some kind of active role in the community has the positive social and psychological effects of encouraging the elderly to be as independent as possible in spite of disability. Second, community living is less expensive than institutionalization.[3]

Maintaining the impaired elderly in the community may be the ideal, and it may save tax dollars, but it is not without cost. It requires substantial support and often personal sacrifice[7] on the part of family members. Nearly three quarters of the disabled elderly who live outside of institutions rely solely on family and friends for necessary assistance.[8] An impaired elder's ability to remain in the community rather than be admitted to a nursing home is often determined more by the characteristics of his or her caregiver than by any other factor.[8,9]

## THE RECIPIENT OF CARE

Stone, Cafferata, and Sangl[6] found, in their national study of the noninstitutionalized impaired elderly and their caregivers, that 1.6 million elderly report one or more limitations in activities of daily living (ADLs), and 42% report difficulty with at least five ADLs. Twenty percent are 85 years of age or older, and 38% describe their health status as poor. Most of these impaired elderly live with family members. Only 11% live alone. This percentage of elderly living alone is a much lower figure than the recent estimate of 33%, emphasiz-

ing society's reliance on family caregivers to sustain the elderly population outside of institutions.

## CAREGIVERS

Characteristics of the caregiver vary widely, but there are common themes. Seventy-two percent[6] to 80%[8] are women. Twenty-nine percent of caregivers are adult daughters and 33% of all caregivers are sole providers of that care. The average age of the caregiver is slightly over 57 years, but 25% of these are between 65 and 75 years old and a surprising 10% are over 75 years old.[6]

This group of caregivers could be considered a vulnerable population based on their socioeconomic status and their self-reported health. Whereas the majority (57.1%) report incomes in the low to middle range, 31% have incomes below the poverty level; 33% rate their general health as poor.[6]

Middle-aged women, who make up a considerable portion of the caregiver population, are at a developmental point in their lives when they have multiple demands on their time and attention and may be experiencing conflict from the pull of their many role obligations.[10] Of all caregivers, 20% report having children under 18 years old, and 31% of caregivers are in the work force.[6]

Stone, Cafferata, and Sangl[6] propose that this work conflict is one of two major stresses for the caregiver, the other being competing family obligations. While only 12% of the women left their jobs to care for a disabled relative, the impact on employment status is greater than this figure would indicate, because many reported cutting back on their hours; 29.4% rearranged their schedules, and over 18% took leave without pay.[6] These figures have been higher in other studies[1] and certainly indicate a considerable sacrifice for people at lower socioeconomic levels.

## CAREGIVER BURDEN

Negative consequences of caregiving for the caregivers themselves include the emotional stresses of coming to terms with the changing role and capability of the older person; the restrictions on time and freedom; the economic burdens, including loss or curtailment of employment; and the detrimental effects on the caregiver's marital, family, and social relationships.[11]

Caregivers are indeed faced with major life restructuring on a long-term basis. One study showed that 44% of caregivers had been providing assistance for one to four years and that, for more than 20%, the time was more than five years. For the majority (80%) this care was provided seven days a week for an average of four hours a day.[6]

Caregivers experience stress to varying degrees and this stress seems to be modified by many complex variables such as the relationship with the care receiver,[10] the functional level of the elder, the type of care given, and the age of each.[11] Cases in which the elder experienced dementia put the caregiver at particularly high risk for stress. Among spouses of Alzheimer's patients, Gmeiner[12] reported that 97% had no time for relaxation and 80% had no

***Caregivers are faced with major life restructuring on a long-term basis.***

relief from patient care. Lack of sleep and fatigue were reported by this group and by Rabins, Mace, and Lucas,[13] who found that 87% of the caregivers complained of chronic fatigue, anger, and depression.

Zarit, Reever, and Bach-Peterson[14] have conceptualized and measured caregiver burden associated with senile dementia. They found a negative association between perceived burden and social support, and a positive correlation was discovered between burden and nursing home admission.[15]

## EFFECT ON CAREGIVER HEALTH

Evidence that caregiver health is associated with the caregiver role has been documented by researchers. Chenoweth and Spencer[16] found that 21% of caregivers had become ill or injured while giving care, and Gmeiner[12] found that 62% of spouses of Alzheimer's patients experienced health problems.

Archbold[17] found that most of the caregivers had some health problems related to their role. They tended to refuse to take action for their own health care if it interfered with the care of the patient, as in the case of the wife who refused to have recommended surgery for glaucoma because she did not want to be away from her husband.

## A MODEL FOR COMPETING SELF-CARE AND DEPENDENT CAREGIVING

The literature supports the idea that as the elder becomes more mentally and physically impaired and less functionally able to care for himself or herself, demands on the caregiver increase. This requirement for care of the elder is conceptualized as a "competing" demand for the resources of the caregiver.[8] These resources include attention, time, energy, and money. Other competing demands are the aspects of the caregiver's life that might require these resources, such as spouse, offspring, employer, and friends, as well as the caregiver's own health needs of exercise, rest, private time, and routine health assessments.

This article proposes that caregivers facing increased requirements for care of an older family member will, when choosing between this dependent care and care of themselves (competing demands), perform fewer self-care actions.

Underlying this proposition is the assumption that the resources of the caregiver are finite, and there are limits to the energy, patience, time, and money that can be expended on all demands before these resources will be overwhelmed. Although the caregiver is capable of self-care, the needed resources are consciously being directed toward caring for the elder. The health-promoting and illness-preventing behaviors that would be directed at safeguarding the caregiver's own health are given a secondary or lower priority.

This notion is supported by Eisdorfer and Cohen,[18] who state that most families prefer to keep the elder at home as long as possible and to expend resources to delay the decision to institutionalize until emotional and financial resources are exhausted, even though this action may result in physical and psychological disorders.

Work by Archbold,[17] Chenoweth and Spencer,[16] Gmeiner,[12] Pratt, Wright, and Schmall[7] reinforce the impression that caregivers put the care of the elder before their own health care requirements.

## THE PLACE OF NURSING IN THE COMPETING DEMAND MODEL

As the caregiver is supporting the waning functioning of the elderly person and attempting to meet his or her own health care needs, a discrepancy may exist between the caregiver's resources and the requirements for care. In Orem's nursing model, this situation is described as a deficit relationship when "care abilities are less than those required for meeting a known self-care demand."[1(p35)] According to Orem, nursing is a legitimate service when such a deficit relationship exists.

In this caregiver model, nursing is conceptualized as supporting the caregiver's ability to provide care for himself or herself and for the elderly person. This care would consist of nursing assessment of the demands of the situation and the resources of the caregiver followed by nursing interventions to provide information and assistance to buttress the capabilities of the caregiver. This capability for care is termed "self-care agency" and is defined as "the *complex acquired ability* to meet one's continuing requirements for *care* that regulates life processes, maintains or promotes integrity of human structure and functioning and human development, and promotes well-being."[1(p105)] Orem states that self-care agency is conditioned by factors that affect its development and operability and that its adequacy can be determined by measuring it against the existing self-care demand.[1]

The caregiver's ability to provide care for self and elder is therefore considered here to be self-care/dependent-care agency. This capability, or agency, of the caregiver is attempting to compensate for the self-care deficit of the impaired elder, whose own self-care agency can no longer keep up with his or her self-care demands. This same agency is being tapped to meet the self-care demand of the caregiver.

Therapeutic self-care demand is defined as "the totality of self-care actions to be performed for some duration in order to meet known self-care requisites by using valid methods and related sets of operations or actions."[1(p88)] Because self-care demand is the total set of actions required to meet health needs at a given moment, the caregiver is using his or her resources to meet personal self-care demands as well as those self-care demands not met by the self-care agency of the impaired elder. This difference between agency and demand or ability and requirement is expressed as a self-care deficit.

Orem's Self-Care Deficit Theory states, as its central idea, that "people can benefit from nursing because they are subject to health-related or health-derived limitations that render them incapable of continuous self-care or dependent care or that result in ineffective or incomplete care."[1(p34)] This model of competing self-care/dependent-care can be conceptualized as the nurse intervening and supporting the caregiver in his or her handling of the self-care deficit between caregiver agency and therapeutic self-care demand. This nursing support is

postulated to strengthen the caregiver's ability to respond to the self-care deficit of the elder.

## CONCEPTS OF THE MODEL

Fawcett and Downs[19] contend that the concepts in a model such as Orem's are too abstract to be tested in nursing research designs. The propositions of such a model are suited to empirical testing of theories that have been derived from or linked to the original abstract framework. Fawcett and Downs propose a three-tiered structure with the broad concepts of the original model linked to the concepts of the theory by way of propositions, which in turn are connected to empirical indicators by means of operational definitions.

This strategy will be used to identify the levels of abstraction of the concepts of this model. The concepts of Orem's General Theory of Nursing[1] will be explained within this competing self-care/dependent-care model as a theoretical definition for this article. The empirical indicators, or the ways of measuring the concepts for the purpose of this exercise, will be described as the third or lower tier.

An elder is the impaired person who receives care. In some cases, both the caregiver and the care recipient are elderly.

Caregiver is defined as the individual considered by the care recipient to be the principal person providing care and taking responsibility for meeting those needs the elder person cannot meet. The individual must consider himself or herself to be a caregiver in this definition.

Impairment of the elder could be considered one of Orem's "conditioning factors"[20] at the conceptual abstract level of definition, because state of health and physiological conditions are included in these factors. For the purposes of this analysis impairment is defined theoretically as neurological, psychological, or physiological conditions that interfere with the optimum functioning of the elder's self-care. The empirical indication is the rating by the caregiver of functional impairment.

Self-care is conceptually defined as "the production of actions directed to self or to the environment in order to regulate one's functioning in the interests of one's life, integrated functioning, and well-being."[1(p31)] The theoretical definition would be activities engaged in by the subject for the promotion of personal health and safety. The empirical indicator for this concept could be the score on a caregiver's health behavior instrument, which describes the caregiver's self-perceived behavior regarding his or her own health.

Self-care deficit is conceptually defined as "a relationship between self-care agency and therapeutic self-care demand in which self-care agency is not sufficient to meet the known therapeutic self-care demand."[1(p31)] It is defined here theoretically as the inability on the part of the elder to meet his or her needs for care. The empirical indicator of this value would be the score on an instrument such as that designed by Gurel et al[21] that measured physical and mental functioning of the care recipient and was adapted to be completed by the caregiver.

Therapeutic self-care demand is defined conceptually by Orem as described above. For the purpose of this analysis it is considered to be all the actions required to meet the health care needs of the elderly person and the caregiver.

Self-care agency has been given the following conceptual definition by Orem: "Self-care agency (dependent care agency) is understood as a complex property or attribute of individuals that enables one to determine requirements for and to take effective action to meet the known, particularized regulatory requisites of individuals."[22(p76)]

The theoretical definitions of self-care agency in this article include the concept of the elder's self-care agency, which is considered to be the ability of the elder to engage in instrumental activities of daily living including decision making and initiation of social interaction, as well as physical, developmental, and hygiene measures. Also addressed here is the theoretical definition of the self-care/dependent-care agency of the caregiver. For this article self-care/dependent-care agency is considered to be the capability of the caregiver to engage in activities to provide care to promote the health, development, and well-being of the dependent elder while simultaneously engaging in activities to promote his or her own health, development, and well-being. Included in this definition is the ability to make judgments on the allocation of limited resources such as time, money, and personal energy. Empirical indicators of self-care agency and self-care agency of a significant other have been developed (Brouns, Evers, Smeets, et al, unpublished data), and a composite score on an instrument designed to measure self-care agency would provide such an indicator.

Nursing agency is defined by Orem at the conceptual level of abstraction as "understood as a complex property or attribute of nurses developed through specialized education and training in nursing sciences and in the art of nursing. From an action perspective it is a human property that is enabling for nurses to engage in the diagnostic, prescriptive, and regulatory operations necessary to design and produce systems of nursing care for persons with self-care or dependent care deficits associated with the health state or health care requirements of persons in need of care."[22(p77)]

In this article, this concept will be defined theoretically as the ability of the nurse to assess the capability and coping skills of the caregiver. Included in this definition of nursing agency is the proficiency to design and implement interventions to reduce any existing deficits between the caregiver's agency and demand and to continually evaluate the effectiveness of these nursing interventions as a means of providing continuing support for the caregiver.

Empirical indicators for nursing agency could be identified as the actions produced by the nursing agency. This indicator could be a type of process measure; that is, the presence of the actions could be evaluated, such as whether a nursing care plan had been initiated and followed or whether an assessment form had been completed. Another approach to empirical indicators would be to designate patient behaviors as the outcomes of nursing care, such as an increased score on a caregiver's self-care

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behavior scale. Such a scale would need to be devised by the nurse from his or her experience with caregivers of the elderly or adapted from the many health behavior instruments.[23]

## IMPAIRMENT AND SELF-CARE AGENCY OF THE ELDER

This model proposes that as an elder becomes functionally impaired as a result of chronic illness or degenerative processes, self-care agency is reduced. This idea is supported theoretically by Orem's conceptual model[20] in which she describes conditioning factors that influence both self-care agency and therapeutic self-care demand. For self-care agency, these factors include such variables as genetic makeup, age, developmental status, knowledge, skills, emotional states, and physiological and psychological health states. Clinical research supports the relationship between aging and physiological function as well as that between chronic illness and aging.[6,24]

## SELF-CARE DEMAND AND SELF-CARE AGENCY

It is proposed that as the agency of the elderly person is reduced, he or she will be unable to meet all needs for personal care unaided. This relationship is addressed in Orem's Self-Care Deficit Theory.[1]

## CAREGIVER AGENCY: A PIVOTAL CONCEPT WITH MULTIPLE RELATIONSHIPS

In this model it is proposed that the agency, or complex capabilities of the caregiver, act to reduce the deficit between the elder's self-care demand and the elder's self-care agency. This reduction is accomplished by direct action on each of these entities. The caregiver supports the agency of the elder by protecting and strengthening and by encouraging rest, nutrition, elimination, and the like, while simultaneously reducing self-care demands by taking them on himself or herself or by delegating the meeting of these demands to another. The idea of this relationship is supported in the literature by Bowers,[25] who conceptualized five categories of caregiving, and by Zarit, Reever, and Bach-Peterson,[14] who synthesized the theory of "caregiver burden." Research support of the relationship appears in the work of Zarit[14,15] and Gmeiner.[12]

Another relationship proposed in this model is the relationship between the caregiver's agency and the caregiver's self-care demand. This relationship is central to Orem's Self-Care Deficit Theory and is supported theoretically by that conceptual model. The idea that the caregiver must use his or her agency to meet the deficit of the elder as well as his or her own needs is supported in the caregiver literature by Soldo and Myllyluoma's conceptualization of competing demands,[8] and by Brody's analogy of elastic that snaps.[26] Research support is presented in the work of Robinson[27] and Gonyea.[28]

## CAREGIVER AGENCY AND CAREGIVER SELF-CARE

According to the model designed by Orem,[1] both self-care agency and self-care demand affect self-care. This concept provides theoretical support for the proposed relationship of this caregiver model, which

also states that caregiver agency and caregiver therapeutic self-care demand will affect the self-care of the caregiver. In addition, this model hypothesizes that the elder's self-care deficit will indirectly affect the self-care actions of the caregiver by this implied competition for the caregiver's agency.

Theoretical support for this relationship is not explicit in the literature but is implied in the work of Brody,[26] who conceptualized the "woman in the middle" who neglects her own health care, and in the work of Pratt, Wright, and Schmall,[7] who discuss the ethical dilemmas of caregiver choices between self and elder.

For research support of the relationship, Archbold,[17] in a small study, found that caregivers failed to engage in health care practices as a direct result of their caregiving. Smallegan conceptualized the act of institutionalization as a breakdown of the ability or agency of the caregiver: "A decision to enter a nursing home is always a result of inadequacy—in finances, health, social supports, emotional strength, or other ability to cope."[29(p364)]

## A SUGGESTED HYPOTHESIS

With increased impairment, identified by Orem[1] as a conditioning factor of self-care agency and therapeutic self-care demand, the elder's self-care agency is unable to keep up with demand and a self-care deficit exists. It is postulated here that as the caregiver attempts to cope with the elder's increased needs for care that the elder is unable to meet, these demands compete for the caregiver's resources. The caregiver may fail to engage in self-care activities as a result of this increased demand on his or her self-care/dependent-care agency. It is therefore hypothesized that as the self-care deficit of the elder receiving care increases, the self-care actions of the caregiver will decrease.

## IMPLICATIONS FOR NURSING RESEARCH

As the population of impaired elderly in the community increases, the health of their caregivers will be a major focus of health care providers and health policy. Because of their firsthand knowledge of the practical needs of the impaired elderly and their primary caregivers, nurses whose practice involves this population should be involved in the leadership of this policy-making effort. To provide for the actual needs of these clients, nurses must perform careful and accurate assessments.

Past efforts at providing support for caregivers have been inadequate and inappropriate.[30,31] The resources mobilized by community agencies and others to support these caregivers of the impaired elderly must be directed toward the real needs of the group. Nurses should conduct qualitative studies that ask the caregivers for their own perceptions of what interventions would really help them to care for themselves and their loved ones. These studies could provide variables for larger quantitative designs to provide data for interventions and evaluations of this growing population. Such research is necessary because, in spite of the large numbers of studies of caregivers,[6,11] there is a dearth of documentation of studies of successful interventions based on the perception of the caregivers themselves.

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The persons who give care to the increasing numbers of elderly can be viewed as a vulnerable population in need of the specific services of nurses. This article proposes a model of competing demands made on the caregiver in which the caregiver is forced to make a choice between the needs of the impaired loved one and the self-care demands required for caring for his or her own health.

Nurses are the appropriate providers to plan and conduct research into the needs of this vulnerable group of clients and to use them as consultants in planning and evaluating interventions to provide support, relief, and assistance that is relevant and meaningful to them in their caregiving mission.

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