Nutrition Education May Reduce Burden in Family Caregivers of Older Adults

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ABSTRACT

The chronic, demanding nature of family caregiving for frail older adults creates a high degree of stress for caregivers, called caregiver burden. Caregiver burden compromises caregivers' emotional and physical health and health-promoting behaviors. Deterioration in caregivers' health and nutritional status may put caregivers at risk for chronic disease, diminish the ability of caregivers to provide care, and impair the quality of life experienced by caregivers and care recipients. Nutrition education may help reduce caregiver stress and maintain caregivers' health and well-being. Mediating caregiver stress may allow family caregivers to meet their societal role, which has intensified because of health care cost containment.

KEY WORDS: family caregiving, caregiver burden, older adults, aging, nutrition education

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INTRODUCTION

The term "caregiver burden" describes the type of chronic stress experienced by family caregivers. Currently, family caregivers assist older adults (age 65 years and over) with daily personal care in more than 25 million US households. In other words, family caregivers provide 80% of all home care despite being uncompensated for the services they perform. By 2007, projections are that the number of caregiving households will increase to over 39 million. recognition that family caregiving is a vital national health care resource came to the forefront of public consciousness when the Clinton Administration signed the Family and Medical Leave Act in 1993. More recently, the reauthorization of the Older Americans Act (November 2000) includes a National Family Caregiver Support Program to assist families who care for older relatives by providing grants to states for supportive services that include individual counseling, support groups, training, and respite care. Including nutrition counseling, education and other nutrition services in federal, state, and local caregiver programs may benefit caregivers by helping them maintain their own health and well-being, as well as enhancing caregivers' ability to provide nutritionally adequate diets and other essential nutrition services to their older adult care recipients.

AGING AND HEALTH CARE USE

Older adults, who comprise 13% of the US population, are predicted to make up 20% of the population by the year 2030. The increased longevity of older adults fosters increased prevalence of disability and functional dependency among the oldest old (age 85 years and over). Visual and hearing impairments, which occur in 13% of adults between the ages of 70 and 74 years, exist in 31% of adults age 85 years and over. At least one third of adults over age 70 years have difficulty with physical activity. In addition, the nutrition-related chronic diseases associated with aging (e.g., cardiovascular disease, hypertension, stroke, diabetes, pulmonary disease, and cancer) occur in 80% to 86% of adults age 70 years and over.

Thus, older adults use 4 times the health care resources used by younger adults. National health care spending, which has accelerated by 6.5% yearly and now approaches 1.1 trillion dollars, reflects the changing demographics of the US population. Measures to curtail rising health care expenditures have promoted the transition of acute and chronically ill people away from hospital-based care into home and community-based care. Although many older adults prefer to recuperate from illness in the home environment, these attempts to curtail rising health care expenditures have driven the dramatic growth in family caregiving. Although national expenditures for hospital care have decreased from 42% to 34% of health care dollars, the number of older adults who rely on family caregivers has grown to over 75% of frail elders. Hence, family caregivers provide a huge pool of unpaid health care labor, with an estimated national eco-
nomic benefit to society of $196 billion. Family caregivers are a population that has been neglected in nutrition research, policy, and practice.

WHO ARE FAMILY CAREGIVERS?

Family caregiving, also called informal caregiving, is defined as the voluntary care provided by a family member, relative, friend, or neighbor to an older adult who cannot perform all of the care alone. The majority of caregivers are the adult children of care recipients. Most often these caregivers are middle-aged females (age 45 to 55 years) who are usually married, employed on a full-time basis, and live in households with a median income of $35,000. Spousal caregivers are typically over age 65 years and constitute 25% to 33% of the caregiving population. Although family caregiving is common to all ethnic groups, it is more common in Asian and African American households (31.7% and 29.4%, respectively) when compared with Hispanic (26.8%) or white households (24%). Although less than one third of family caregivers live with their care recipient, they provide from 4 to 8 hours of service daily, for an average of 4½ years.4,5

Role of Family Caregivers Traditionally, the caregiving role involves providing personal care to older adults for activities of daily living, such as bathing and eating. Close to 98% of caregivers also assist with daily household chores, grocery shopping, meal preparation, and providing transportation and other instrumental activities of daily living.5,6 However, the movement toward the provision of health care into the home setting has altered the nature of the relationship between health care professionals, patients, and family caregivers. Previously, in the hospital arena, caregivers provided emotional support to patients while depending on the knowledge and skills of physicians and other clinical personnel to make competent medical choices and deliver high-quality care. In the home environment, caregivers and patients are now required to be more actively involved in the delivery of health care by assuming decision-making and case management responsibilities.7 Consequently, the caregiving experience of the twenty-first century may be imposing an unprecedented amount of stress on the caregiver.

DEFINING CAREGIVER BURDEN

Caregiver burden incorporates the problems and challenges that family caregivers face while participating in the caregiving role, the physical and psychological reactions to being a caregiver, and the conflicts a caregiver experiences as demands for caregiving interfere with the caregiver's customary life. Variables associated with the dimensions of caregiver burden can best be understood within the domains of the broader conceptualization of stress first put forth in Lazarus and Folkman’s transactional model of the stress process.8 In this model, sources of stress (ie, “stressors”) include environmental stressors that range from daily disturbances such as driving on the highway to catastrophic events such as living through an earthquake, other life-related events such as relocating or going through a divorce, and health-related events such as being diagnosed with a serious condition, having surgery, or hospitalization.9 The occurrence of stressors arouses an individual process of assessment and interpretation of stress (ie, “appraisal”), in which the individual makes a judgment of the implications of the stress.10 Stress can be appraised as harmful or beneficial, which often depends on the coping skills and resources possessed by the individual experiencing the stress.11 For example, whereas one caregiver may feel stressed out when assisting an older adult with food shopping, preparing meals, and food consumption, another may handle it with a sense of reward.

Understanding why one individual may appraise family caregiving stressors as harmful and another individual sees them as beneficial is further elucidated by Pearlin et al’s adaptation of the stress process model to family caregiving (Figure).12 In their model, stressors are distinguished between primary and secondary stressors. Primary stressors encompass the duration, effort, and energy involved in caregiving as well as the cognitive and functional status of the older adult care recipient.13 Secondary stressors incorporate the strain a family caregiver experiences from demands on the caregiver’s time, which conflict with family life, work, social activities, and finances.14 The caregiver’s level of self-esteem, self-confidence, role captivity (ie, feeling trapped in the caregiving role); competence, and mastery of the caregiving role are other variables that function as secondary stressors.15 Another aspect of Pearlin et al’s model is the background and context of caregiving. Individual characteristics, such as the caregiver’s age, gender, education, income, values, commitments, and relationship to the caregiver, all work to influence the process of appraisal.16 Other individual variables, such as nutritional status, may also function in a caregiver’s resistance or vulnerability to experiencing caregiver burden.17

Both Lazarus and Folkman’s and Pearlin et al’s models emphasize the role of coping skills and social support as factors that function during appraisal to mediate (ie, diminish or enhance) the impact of stressors.18 Coping skills include seeking information, problem solving, and engaging in activities that allow the release of stress.19 Taking time for oneself, eating, drinking alcohol, smoking, exercising, reading, watching television, and taking medication are among the activities that caregivers engage in to manage stress.16 Stressors and appraisal influence the adaptational outcomes that individuals experience within the stress process. Adaptational outcomes include changes in the caregiver’s physical, psychological, and emotional health.20
Evidence of Outcomes of Caregiver Burden  Most of the research on caregiver burden outcomes has focused on psychological outcomes such as the occurrence of depression. Symptoms of loneliness and depression or clinical depression are widely present in family caregivers, with prevalence rates up to 47% in some caregiver populations. Although it is indeed possible that the subjective or emotional response to caregiving will be positive because of personal reward from the act of giving, negative feelings of unhappiness, guilt, anger, fear, and anxiety are other typical emotions expressed by distressed caregivers. Impaired quality of life is also associated with caregiver burden.

Only a few studies have been designed to objectively investigate the impact of family caregiving on the caregiver’s physical health status. Most reports on caregiver outcomes are from descriptive studies in which the majority of caregivers felt that their health was deteriorating in relation to the degree of caregiver stress they were experiencing. However, increased incidence of physical impairments, immunosuppression, elevated insulin levels, chronic fatigue, and insomnia has been documented in caregiving populations.

Although preventive health behaviors such as eating a balanced diet, limiting alcohol consumption, restricting smoking, and engaging in regular exercise have not been investigated methodically in caregivers, reports from a few studies show that family caregivers experience alterations in appetite and body weight. In a study by Gallagher et al of 190 caregivers of individuals with Alzheimer’s disease, 39 (21%) experienced weight gain, 32 (17%) increased appetite, and 16 (8.5%) decreased appetite after caregiving began. Fredman and Daly found that 40 of 200 (19%) caregivers experienced a weight gain or loss of 10 pounds or more, with weight change significantly associated with increasing levels of caregiver burden and stress. In addition, Sisk found that both caregiver age and subjective burden were significant predictors for poor scores on the nutrition subscale of the Health-Promoting Lifestyle Profile questionnaire. Sisk also found that age and objective burden were associated with reduced levels of exercise. Therefore, caregivers experiencing high caregiver burden are more likely not to participate in health-promoting behaviors, including eating a balanced diet.

Additionally, the frailty of older (usually spousal) caregivers, who provide the highest intensity level of care, contributes to caregiver burden as their own health problems often go unattended. These caregivers report an inability to find time to rest, exercise, recuperate from illness, and take medications. Spousal caregivers also report higher rates of chronic health conditions such as hypertension. One dramatic statistic that elucidates the impact of caregiver burden on health outcomes is that spousal caregivers have a mortality risk that is 63% higher than non caregiving spouses.

In summary, the chronic nature of caregiving, the intensity of activities that caregivers perform, and conflicts arising from demands on caregivers’ lives are sources of caregiver burden. Caregiver burden often manifests in a variety of physical, psychological, and metabolic problems that increase health risk and contribute to deterioration in caregivers’ quality of life. In addition, caregiver burden contributes to complications of care, poor outcomes, and reduced quality of life for the older adult care recipient. Nursing home admissions and neglect and abuse of older adults are other serious consequences of caregiver burden. It is possible that attention to the nutritional status and nutrition education needs of family caregivers may mediate or moderate some of the negative outcomes associated with caregiver burden.

CAREGIVER EDUCATION  Nutrition education has only occasionally been a component of successful caregiver education and support programs. For example, small-group educational sessions with family caregivers show not only improvement in caregiving knowledge and abilities but also increased occurrence of preventive health behaviors (ie, eating regularly, not drinking, not smoking, engaging in physical activity, and sleeping). Therefore, when caregivers receive education, caregiver burden may lessen. Altering the factors associated with development of caregiver burden may also improve caregivers’ and care recipients’ quality of life during the caregiving process. However, researchers and practitioners have not yet recognized the potential for unmet nutritional needs or risk for malnutrition in family caregivers themselves — or their need for in-depth nutrition education programs. Yet changes in food items and nutrients consumed by caregivers may contribute to the adverse effects of stress.
on their health status and risk. Changes in appetite, amount of food intake, eating habits, and the food groups consumed have been documented in other human populations experiencing chronic stress. Furthermore, in recent studies, chronic stress has been linked to hypercortisolism, hyperlipidemia, and food intake-related obesity that affect morbidity and mortality.

Experiencing caregiver burden may prevent family caregivers from recognizing their own need for or their ability to engage in nutrition education activities. However, caregivers have demonstrated a substantial need for nutrition education by receiving low scores on a nutrition knowledge test that used the Food Guide Pyramid to evaluate caregivers’ ability to determine the nutritional adequacy of their care recipients’ dietary intake. Additionally, when caregivers were evaluated from the perspective of their nutrition care behaviors toward their care recipients, caregivers could only recognize gross signs of malnutrition.

IMPLICATIONS FOR RESEARCH, PRACTICE, AND POLICY

There are no studies to our knowledge that investigate or evaluate nutrition education interventions for family caregivers, especially those that focus on nutrition risk in caregivers themselves. However, the existence of negative health outcomes that have nutritional components in caregiving populations (as described above) suggests that caregivers could benefit from maintaining or improving their nutritional status via nutrition education.

Because of this gap, researchers should design studies that measure the effectiveness of nutrition education in caregiver populations to document its ability to help family caregivers maintain their own health, functionality, and quality of life (as well as that of their care recipients), reduce caregiver burden, and enhance the ability of caregivers to provide chronic care. In designing such studies, researchers need to account for differences in various caregiver populations and identify elements for successful interventions specific to types of caregivers. For example, the nutritional and educational needs of caregivers of individuals with Alzheimer’s disease may vary from those of caregivers of physically frail older adults, those dealing with cancer or renal disease, or those dependent on home infusions. These caregiver populations may be found through national caregiver organizations such as the National Family Caregivers Association and the National Alliance for Caregiving, federally funded programs for older adults such as the Administration on Aging, state departments or units on aging and state-funded caregiver resource programs, local caregiver support groups, acute and long-term care discharge planners, outpatient clinic or ambulatory care staff, independent home health agencies, and advertising in caregiver newsletters. However, caregivers’ responsibilities may limit access to caregiver populations. Research design should incorporate data collection at sites convenient to caregivers (eg, while caregivers sit with their care recipients in waiting rooms).

General nutrition education topics for caregiver interventions could include eating a balanced diet to mediate the stress process, managing impaired appetite, the need for adequate protein and other nutrients to maintain strength, quick and easy healthful menu items to prepare, tips for eating a healthful diet to avoid unintended weight loss or gain, using the Food Guide Pyramid, understanding dietary guidelines, interpreting food labels and nutrition messages in the media, and nutrients to consume to help prevent disease and illness. Caregiver burden may also decrease substantially with enhanced ability to provide quality nutrition care to their older adult care recipients by learning about topics such as consuming energy-dense and high-protein foods, avoiding food–drug interactions, and managing therapeutic diets when intervening with care recipient populations.

Overall, the goal of such nutrition education should be to maintain or improve dietary behaviors while caregiving and decrease caregivers’ risk for chronic disease and other negative outcomes of caregiver burden. However, simply providing nutrition knowledge to caregivers by offering handouts on topics such as those suggested above is not likely to result in dietary change or to reduce caregiver burden and improve caregiving. To be successful, nutrition educators should use or modify educational methods and strategies proven effective in other free-living adult populations. Effective nutrition education programs for adults and older adults use research-supported theory such as expectancy-value theories like the Health Belief Model or social learning theories. These theories link change in health-related behaviors to an individual’s knowledge that he/she is vulnerable, belief that he/she is able to change, and awareness that changing dietary behavior decreases risk. It is likely that caregiver burden will prevent some caregivers not only from recognizing their own nutrition and health care needs but also from feeling motivated to contend with these issues. Thus, behavior change theories, as currently conceptualized, may need modification to apply to the experience of caregiver burden. Nevertheless, nutrition educators can motivate caregivers by using strategies based on these adult-based theories and by making caregivers active participants in dietary behavior change. For example, caregivers could assess their own dietary intake with tools like the Healthy Eating Index, establish goals for dietary change, develop a diet plan, and record their food intake.

The comprehensive needs of family caregivers are clearly more than a research and education issue; they are a public policy issue as well. Although the first step to influencing public policy is to demonstrate the benefits of nutrition services through research-based interventions, another way to influence policy is to make sure the word “nutrition” appears in lists of services to be covered by Congressional bills, resolutions, legislation, guidelines, rules, and regulations. For example, as policy makers are addressing family caregiving in public funding, they need to incorporate nutrition education
or nutrition services in the array of current federal, state, local, and private caregiver programs so that resources will be allocated to develop and implement nutrition education materials and methods that focus on stress reduction, health promotion, and disease prevention for family caregivers.

Another opportunity for influencing family caregiver policy is the success of the Medical Nutrition Therapy bill. Since one of the driving forces in the growth of family caregiving is the continued limitation in Medicare coverage for professional home health services and as the demand for home care services by older adults will continue to increase, lobbying efforts that advocate for expansion of Medicare benefits for nutrition therapy could include coverage for nutrition education or services for at-risk groups such as caregivers.

Concern for inadequacies in nutrition education and other nutrition services available to older adults has been raised in this journal. We now suggest that the lack of nutrition education programs for the family caregivers of older adults receives attention. Nutrition educators are likely to find not only a needy but also a receptive audience among family caregivers. Helping caregivers to help themselves and, in turn, help their older relatives through nutrition education is a worthy challenge of this century.

REFERENCES


