The Stress of Caregiving in Midlife Women

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Clinicians play an important role in assessing the sources of stress in their patients, including stress from caregiving. Interventions to reduce this stress may lessen the negative consequences of caregiving in midlife women.

Society expects that midlife women will assume major responsibility for "informal" caregiving for children, spouses, parents, other relatives, or a mix of these individuals. This type of informal caregiving is defined as "unpaid provision of assistance to someone who is incapacitated or needs help."[1] The typical caregiver for older adults is female, married, and middle-aged. Half of all women caregivers work outside the home, and some of them have an older adult needing care living in their home.[2] Caregiving has been identified as a chronic stressor that may have negative health consequences, restricting personal life, social life, and employment.[3-5]

NEGATIVE AND POSITIVE EFFECTS OF CAREGIVING

Midlife women are more likely than men to take on the role of primary caregiver, care for a spouse or a parent, and spend more hours caring for sick relatives. They also provide more hands-on care with activities of daily living such as housework and meal preparation.[5]

As a result of reforms to health care systems in both the United States and Canada, there has been a shift in caregiving responsibilities from institutions to communities, in particular to families.[6] In addition to an aging society, factors that have influenced the growing demand for informal caregivers in the United States include medical advances, shorter hospital stays, limited discharge planning by hospitals, and the growth of home care technology.[1] If informal caregivers were paid for their work, estimated costs would have totaled $196 billion in 2002 and $306 billion in 2004.[7,8]

Family caregiving has both positive and negative consequences. While some caregivers experience an improved sense of well-being linked to personal growth and fulfillment,[1] for the majority this role has negative consequences. Caregivers report health effects including psychologic distress, lowered life satisfaction, interpersonal conflict, social isolation, sleep disturbances, disturbed eating patterns, higher blood pressure, and a variety of physical problems.[3,9] As well, informal caregivers face problems associated with lack of information, training, support, and respite services.[5]

Although the positive and negative health consequences of caregiving have been well described, the effects on midlife women who are "in the middle"—caring for growing children at the same time they care for aging relatives—have not been well documented.[10] These women have been referred to as the "sandwich generation." As women in developed nations are having first children at a later age, it is likely this phenomenon will increase. In a study of 933 women ages 40 to 55 in the Netherlands, 29% were responsible for children in their household and also provided help to their parents or parents-in-law.[10]

LONG-TERM EFFECTS OF CAREGIVING

Morbidity, mortality, and financial problems have been associated with informal caregiv-

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ing. Psychologic and physical morbidity are extensively discussed in the literature, but the relationship of caregiving to mortality is less clear.[4,11] In one study, older spousal caregivers with mental and emotional strain had a 63% greater risk for mortality within 4 years than did noncaregivers.[12] However, a population-based study in Ireland did not support this conclusion, possibly because age and initial health status were not considered.[13]

Perhaps the most serious long-term effect for female informal caregivers is financial. The financial toll results from loss of paid employment, accrual of Social Security benefits, retirement benefits, and health insurance.[1,14] Many women who leave paid employment to become informal caregivers never return to paid employment, and those who do return to work after a caregiving hiatus may be forced to accept lower wages.[1,15,16]

It is possible that loss of money as well as professional and occupational opportunities leads to reduced self-confidence and ability to compete in an ever-changing employment market. For those midlife women who have little or no support from family or social networks, the results are likely devastating financially, psychologically, and socially.

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SIMULTANEOUSLY, MENOPAUSAL SYMPTOMS

Added to caregiving-related stress, midlife women encounter symptoms associated with the menopause transition. For several decades, the menopause literature focused on the prevalence and severity of menopause symptoms. Stress was pictured as a result of symptoms or attributed to the "empty nest."[17] Researchers now acknowledge that there are multiple sources of stress in midlife women's lives, including children's health, parenting, relationships with partners or family members, caring for sick or elderly relatives, lack of time for oneself, income insufficient to meet personal and family needs, unemployment or employment, lack of confidence, and lack of sleep.[18] But only a few researchers have studied the interplay of perceived stress, menopause symptoms, and the caregiving role.

Freeman and colleagues found that perceived stress has a strong independent contribution to irritability, mood swings, anxiety, concentration difficulties, and headache symptom severity.[19] Woods et al examined role burden, perceived stress, and menopause symptom severity.[20] In the Seattle Midlife Women's Health Study, increased role burden was found to be associated with a significant increase in stress, but perceived stress levels were not related to hot flash severity. In this study, one aspect of role burden was caregiving.[20]

Although data from these 2 studies may appear conflicting, the symptoms examined were different, and the stress associated with caregiving was not independently studied. Further, only symptom severity was examined in both studies. Other important aspects of symptoms, such as symptom perception, frequency, and distress or bother, were not examined.

It seems logical that stress accumulation from role overload and burden, coupled with lack of support, may be an important factor and should be examined further. And, as the health care industry relies ever more heavily on volunteer informal caregivers, it seems likely women's caregiving burden will increase. Studying the interplay between caregiving, stress, and all aspects of symptoms associated with the menopause transition may uncover important areas to target interventions aimed at easing all three. Studying and understanding the effect of increased well-being in women who find caregiving to be fulfilling may lead to the development of interventions that assist those who experience negative consequences of their caregiving roles.

WHAT SHOULD WE DO?

There are abundant data that inform us of the burden informal caregiving places on midlife women. Everyone from program planners to policy makers must act together to provide accessible, affordable, and innovative support services and programs that remove some of the strain associated with informal caregiving. There is a strong need to involve caregivers locally, regionally, and nationally in developing and implementing policy.[21]

It is not necessary to reinvent the wheel. Excellent models of care already exist. For example, in some states, under the Medicaid program, a waiver can be obtained in which funds are applied to day care or in-home help. This is available to a family member who is eligible for nursing home care but has a volunteer informal caregiver that allows them to remain at home.[22] These funds re-

TABLE. Sampling of National Resources for Caregivers

Eldercare Locator	(800) 677-1116	www.eldercare.gov
Family Caregiver Alliance	(415) 434-3388	www.caregiver.org
Medicare Hotline	(800) 633-4227	www.medicare.gov
National Alliance for Caregiving	(301) 718-8444	www.caregiving.org
National Family Caregivers Association	(800) 896-3650	www.nfcacares.org

duce family financial burden and cost the state significantly less than institutional care.

The weakness of this model is that only the indigent qualify. Similar models could be instituted that provide free respite services or even funding to informal caregivers without Medicaid support. It would be extremely helpful if Social Security benefits were extended to informal caregivers by calculating the financial benefit of their caregiving activities and using this calculation in determining their qualification for Social Security benefits.

Clinicians should be familiar with the Family and Medical Leave Act, which provides some employees as much as 12 weeks of unpaid leave per year and includes job protection.[23] This program is an important resource for caregivers who are forced to take time off from their job.

Health care providers play an important role during office visits in assessing the sources of stress in midlife women's lives, including stress from caregiving. A one-time assessment is insufficient, as caregiving responsibilities and all sources of stress are dynamic. An excellent, easy-to-administer tool to assess caregiver stress is available from the Massachusetts Executive Office of Elder Affairs.[24] In addition, clinicians can connect caregivers with resources for assistance. To do this effectively, clinicians should keep abreast of educational and financial resources, as well as counseling and respite services. See Table for a sampling of national resources for caregivers from the American Medical Association.[25]

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FOCUSPOINT

Perhaps the most serious long-term effect for female informal caregivers is financial.

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on the stress
of caregiving in midlife,
see page 47.

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