Strategies to Ease the Burden of Family Caregivers

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In this issue of JAMA, Adelman and colleagues describe an older woman who attempted suicide to escape the overwhelming burdens of caring for her ill and debilitated husband. This case starkly illuminates the despair that family (and friend) caregivers can feel when supporting frail or disabled relatives, and the failure of US health care to support them. Half a century ago when Medicare began, few people lived long with disabling chronic illness and family supports were more readily available. Today’s 65-year-olds, and all who come after, are likely to experience several years of needing another person’s help in the last phase of life. Many will find such help difficult to obtain; few live near large extended families, and few have younger family members who can afford to leave paid work to provide unpaid care of indefinite duration.

Health care delivery services have not adapted to the needs of aging Americans or their caregivers, despite having anticipated both for years. Unpaid and untrained family caregivers must handle medical devices, medications, and treatments that were once restricted to clinicians. Indeed, family caregivers provide most of the hands-on care—often for years without a break, without pay, vacation, recognition, backup, or help. Medical records typically do not even have a place to identify these family caregiver(s) or to document an assessment of their ability to provide the hands-on services that their frail elder needs. Privacy requirements make clinicians inappropriately wary of sharing information, and the appeal of not knowing keeps many from asking about the home situation. The end result is widespread and unnecessary suffering, isolation, fear, error, and at times bankruptcy, affecting both the elderly disabled population and their family caregivers. Without a vigorous response by clinicians and policy makers, this situation will worsen. The number of Americans older than 85 years, who are at most risk of frailty, is projected to double between 2000 and 2030, and to double again by 2050, while the ratio of potential caregivers for each person older than 80 years is estimated to decline from 7:1 in 2010 to 4:1 in 2030.

To mitigate caregiver burden, clinicians should identify caregivers and ask them about their particular circumstances. What resources do they have? What costs do they bear? How will they manage? What is their backup plan? How are they coping?

Caregivers should demand coherent, practical, and comprehensive care plans, and clinicians should engage caregivers in developing them. Whenever new tasks and obligations arise, training and support for family caregivers are essential. Every home situation has its breaking point, at which the caregivers or the frail elderly person will experience a failure that precludes continuing with the previously established arrangements, and clinicians must try to detect this risk through frequent monitoring. When problems are identified, clinicians should intervene and try to prevent a breakdown in care at home.

Accomplishing the tasks imposed by medical care can require remarkable efforts by the frail elderly person and the family caregiver and deliberately seeking to reduce the complexity and time demands can help: eg, simplify the medication schedule or diet instructions, provide a motorized lift or a video camera monitor, make home visits, and obtain consultations and diagnostic tests only when they are likely to contribute substantially to the care plan. Going to the home to see the patient and caregiver in their environment provides opportunities to observe and ask about the caregiver’s burdens, capabilities, and needs. Community agencies and neighbors need effective methods to identify people living with progressively disabling chronic conditions and provide support. Some “apps” (software applications) facilitate electronic communication of care plans and coordination of all services, including the family caregiver(s). Reviving neighborliness and supporting volunteer efforts are promising strategies for improvement.

Family caregivers often lose contact with friends, neighbors, relatives, and social groups such as faith communities and civic organizations. Frequently, no one is still visiting and talking with the caregiver when he or she most needs help, whether needing someone to bring groceries or do minor home repairs, or needing sympathy and encouragement.

Society should honor caregiving as a valued and expected part of life, rather than as an awkward gap in the caregiver's work history. Having stories of coping with frailty and caregiving in popular media would help by making the experience familiar and illustrating the possible roles. Employers can help substantially by providing flexible work hours, time-banking to share paid time off among employees, and counseling and referral, such as through employee assistance programs. Clinicians can help by ensuring that the practice provides a mature and experienced staff person who knows about supports available in the community, helps families to make use of the appropriate resources, and advocates in policy settings to ensure support for an adequate supply of these services. Physicians should be knowledgeable advocates when the city, county, and state budgets for services such as Meals on Wheels or home repair services are set.

Federal policy has been inattentive to family caregiving. For example, payment to hospitals and physicians for “meaningful use” of electronic medical records does not require identification of the responsible caregiver for patients needing this...
support. While most developed nations assure that family caregivers have health insurance, respite, continued contributions to retirement security, income, and in-home practical support, the United States does none of these—except in capacity-limited and time-limited programs. The United States stands alone among developed countries in spending nearly one-fifth of national productivity on health care, and only about the same on social support. By comparison, other developed countries spend about the same total, but twice as much goes to social support as to health care. Elderly Americans are entitled to receive even the least valuable of medical interventions but have only scarce safety net resources for food, housing, transportation, and caregiver support. The difference between an entitlement and charity shows up as a relative overinvestment in health care and underinvestment in supportive services in the United States.

The health care system provided by the Department of Veterans Affairs (VA) has moved ahead in providing better support for family caregivers (with “family” defined by the veteran). For any veteran in the home-based primary care program who has activities of daily living dependency and is living in the community, the clinical record must indicate who is providing personal care and support, and the team that provides care must have negotiated the care plan with the family caregiver. The record must also show caregiver responses to a set of screening questions about burden (Zarit Burden scale, short form, 4 questions) and a plan for meeting caregiver needs. In a trial program for veterans with serious brain injury or polytrauma, the VA pays a stipend to some veteran-designated family caregivers, which may be the first time that Congress has authorized payments directly to a family caregiver, aiming to reduce the need for institutional care. In many ways, caregiving defines the essentially shared nature of family life, from raising children to supporting older family members living with progressive disability. Many caregivers speak to the privilege of selfless service to a loved one, even as they recount their burdens. Society will do well to nurture these human bonds, even while improving the reliability of support. Rosalynn Carter once memorably pointed out, “There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.”

Family caregiving is profoundly important as a tangible expression of the bonds of love and obligation. However, caregiving can also devastate families and individuals. Now that most people will need caregivers for several years in the last part of life, the United States needs better policies and programs to support family caregivers.

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REFERENCES