

# Health as a Family Affair

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If your parents are in their 80s, you probably have a conditioned response to middle-of-the-night phone calls: “What happened?” The first time, it may be your father who’s in trouble, and your mother is calling from the hospital. When he returns home, she becomes the de facto caregiver, despite being equally elderly and hardly up for the responsibility. The next phone call may be about your mother — perhaps she’s had a fall, and your sibling is calling from the hospital. Now, care becomes more complicated: the siblings negotiate, one of your sisters volunteers to take primary

responsibility, even move in, and her life changes. She cuts back to part-time work and takes over managing your parents’ medications, appointments, and check-book. Each successive call brings more responsibilities and decisions — a home health aide, a life alert bracelet, equipping their home with grab bars and nonslip floors, working out coverage during your sister’s trips and vacations. Resources become strained, emotional health is challenged, and sometimes physical health suffers.

Despite the substantial burden borne by informal caregivers, our society has only recently recognized that our conception of illness as solely an individual experience is too narrow. For many patients with chronic illness, the majority of care is delivered not through health care institutions but in the home, by spouses, parents, adult children, and other informal caregivers. Baby boomers are increasingly visible in medical offices accompanying their elderly parents to appointments; parents leave the workforce or choose positions with less demanding hours to care for disabled chil-

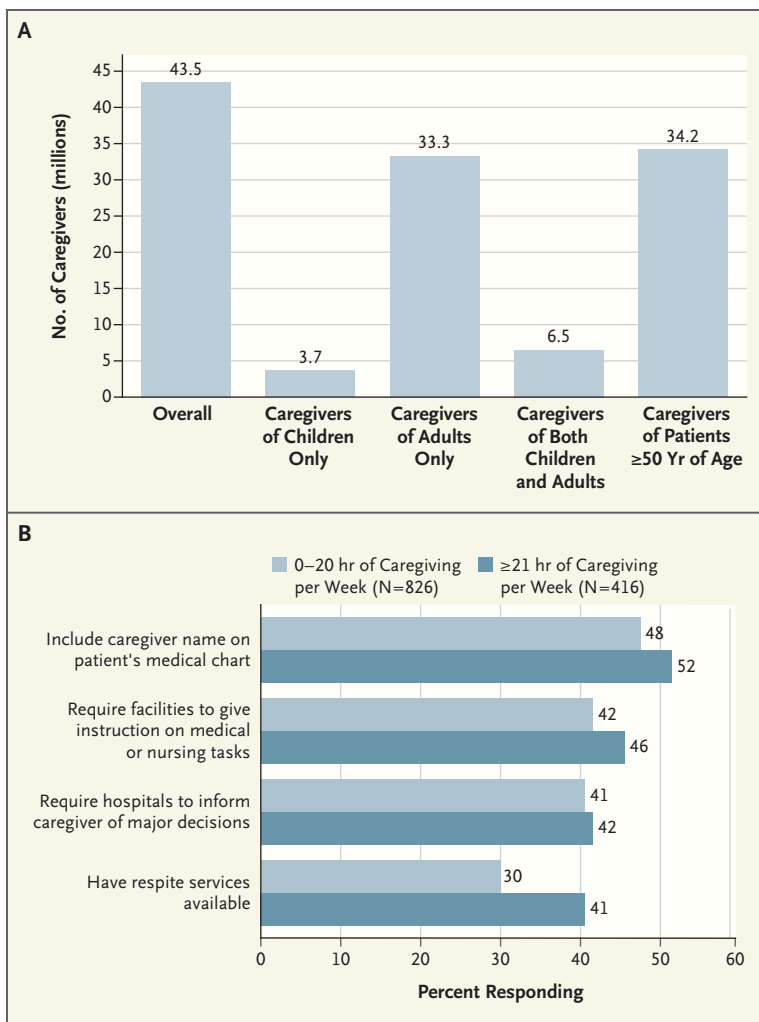
dren; and spouses take on household responsibilities to cover for their ill partners, while also managing their medications and health care. Demand for home-based care is increasing as the U.S. population ages, yet the supply of informal care is shrinking, as a growing proportion of households have two working adults with far less ability to provide “free” informal care. The preferences of patients and families are also shifting toward informal care. These changing dynamics necessitate a rethinking of our

concept of illness to include the entire family.

At last count, there were nearly 44 million adult caregivers in the United States (see graphs).<sup>1</sup> Although care provided by informal caregivers is rarely compensated, there are real costs — to the caregiver and to society. Time spent providing care precludes spending time on other productive activities such as paid work and unpaid work at home. Perhaps more important for the health care system, caring for a family member has been shown to have measurable negative effects on caregivers’ health, especially if the patient has a condition, such as dementia or a mental illness, that tends to disrupt emotional relationships. As Cameron and colleagues report in this issue of the *Journal* (pages 1831–41), family caregivers often have symptoms of depression when the person for whom they’re caring undergoes a health shock. Their quality of life is diminished,<sup>2</sup> and their risk of death increases.<sup>3</sup>

The picture is more complex than this grim summary suggests, however. Caregivers also find fulfillment and purpose in their responsibilities. And patients benefit from family caregivers’ commitment, the continuity of their care, and the trust and emotional bond they share with their caregivers. Effects can be bidirectional: a patient’s health affects that of the caregiver, and the well-being of the caregiver affects that of the patient. The complete picture of illness is thus a *mélange*

***Considering the family as a whole in clinical decisions and treatment plans can provide direct benefits to the patient, and family members deserve care — medical and psychological — as well.***



**Estimated Numbers of Informal Caregivers in the United States (Panel A) and Helpfulness of Caregiving Support Policies (Panel B).**

Data are from the AARP Public Policy Institute and the National Alliance for Caregiving.

of the strains and joys of disease and caregiving, experienced by both patient and caregiver.

Noncaregiving family members are affected as well, since they also care about the patient.<sup>4</sup> Children of ill parents, for example, may feel anxiety even if they're too young to take care of anyone. Noncaregiving family members may become ill and impose additional demands on caregivers. And effects may extend to other household members, through

emotional stress, financial burden, and other mechanisms.<sup>5</sup> Outcomes for noncaregiving family members can be substantially affected and are relevant to a family-centric perspective.

Caregiving dynamics have implications for the care patients receive. Negative effects on caregivers' well-being can limit their ability to provide high-quality care, so it's in patients' best interest for caregivers to be healthy. As deleterious health effects from

caregiving accumulate, caregivers may become patients themselves and enter the health care system. Recognition of the spillover effects of caregiving highlights the interaction between patient outcomes and caregiver outcomes.

Although the patient is traditionally the focus of clinical care, acknowledgment of effects on the family suggests a better approach. Considering the family as a whole in clinical decisions and treatment plans can provide direct benefits to the patient, and family members deserve care — medical and psychological — as well. The intertwined relationships within a family unit can help optimize outcomes when interests are aligned but can create problems of allegiance when interests conflict. Home-based therapies, for instance, may benefit patients but add to a caregiver's burden. Conversely, institutional care may take caretaking pressure off family members, yet be suboptimal for the patient. Increasingly, however, win-win models are emerging, such as “continuing care” retirement communities that address the needs of both spouse caregivers and patients. When interests aren't aligned, consideration of the net family benefit may permit recognition of competing interests and provide a way of understanding the entire picture.

Recognizing that illness affects a patient's entire family allows us to address the full impact of serious or chronic disease. Just as our perspective on infectious diseases encompasses more than just the individual patient, a broad scope of vision makes sense with regard to patients who require ongoing care. We can begin by focusing on the whole family's needs for

treatment and support, outcomes research that includes family members as well as patients, and financing and payment mechanisms that cover all who are affected by illness. Addressing health at a societal level means considering illness's broad effects; patients' family members will eventually be patients themselves, and their experience with others' health will affect their own.

Today, consideration of the family perspective is often integral to hospice care: when, for instance, your elderly mother ends up in the emergency department and a CT scan reveals massive stroke, discharge to hospice generally takes a family-centric view. Although she may be medically unstable, spending your nights in hospital chairs is untenable for you and your siblings' emotional health. So your needs are balanced with your mother's, and you collectively decide to transport her home despite the medical risk, for the benefit of the family as a whole.

But such a perspective is far less commonly adopted during other phases of life. Full consideration of what's happening to a family — in terms of time, finances, and health — during the illness of one of its members will

allow us to care for all involved and develop interventions and policies to support them and, in turn, the patient.

Potential interventions run the gamut from provider-level actions to system-level change. Family members' names can be included in the medical chart. They can be included in decision making and trained in care tasks. Screening can identify any mental health needs early. Accessible and attractive respite care services (and insurance covering them) can relieve caregivers' burden, allowing family care to continue with fewer deleterious effects. Policies providing financial support for caregiving — through mechanisms such as paid leave, government payments, and tax credits — are on the distant horizon but could alleviate the financial burden. Approaches to care that acknowledge all relevant people and effects will result in more efficient allocation of resources than do piecemeal approaches.

Of course, the definition of family is complex and may extend beyond traditional bounds; our attention should not be limited by semantics. The point is that disease does not exist in a vacuum, and the networks within which people live may have

intertwined benefits and harms. Our focus on a given patient cannot blind us to illness's effects on others — others in the room, at home, or connected by telephone — if we're to improve health for both patients and society at large.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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1. National Alliance for Caregiving, AARP Public Policy Institute. Caregiving in the U.S.: 2015 report. June 2015 (<http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>).
2. Prosser LA, Lamarand K, Gebremariam A, Wittenberg E. Measuring family HRQoL spillover effects using direct health utility assessment. *Med Decis Making* 2015;35:81-93.
3. Perkins M, Howard VJ, Wadley VG, et al. Caregiving strain and all-cause mortality: evidence from the REGARDS study. *J Gerontol B Psychol Sci Soc Sci* 2013;68:504-12.
4. Bobinac A, van Exel NJ, Rutten FF, Brouwer WB. Health effects in significant others: separating family and care-giving effects. *Med Decis Making* 2011;31:292-8.
5. Wittenberg E, Ritter GA, Prosser LA. Evidence of spillover of illness among household members: EQ-5D scores from a US sample. *Med Decis Making* 2013;33:235-43.

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