

VIEWPOINT

The Critical Role of Caregivers in Achieving Patient-Centered Care

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Achieving high-quality, cost-effective medical care remains an elusive goal of the US health care system, but there is widespread agreement that patient-centered care will be a key ingredient.¹ Yet for frail elders and patients with advanced illness, many of whom have multiple chronic diseases, patient-centered care is impossible without caregiver involvement. Although advocacy groups such as the National Alliance for Caregivers have long endorsed attention to family members and prominent research organizations such as the newly created Patient-Centered Outcomes Research Institute mention families in their research agendas, the critical role of caregivers deserves considerably more attention from clinicians.

Who Depends on a Caregiver?

At any time, an estimated 42 million Americans serve as caregivers to adult patients, and, on average, they spend 20 hours per week on caregiving.² Caregivers help with shopping, cooking, and other "independent activities of daily living" and also assist with bathing and dressing and other basic "activities of daily living." Nearly half of all caregivers report responsibility for complex medical tasks that often are the province of a professional nurse or trained technician.³ These include providing wound care and treating pressure ulcers, administering parenteral medications and intravenous fluids, maintaining feeding tubes, and operating medical equipment such as mechanical ventilators and dialysis machines, along with dispensing oral medications and preparing special diets. The majority of these caregivers are middle-aged women caring for aging parents.³

Most recipients of caregiving are elderly persons, and many are in the last stages of life. Epidemiologic studies confirm that substantial disability characterizes the final year of life for the majority of patients, and this disability typically necessitates caregiver involvement. In the year before death, only 17% of individuals experience no disability, 22% have persistent severe disability, 18% have accelerated disability, and 24% have progressive disability.⁴ Some of these patients have advanced organ failure and experience frequent exacerbations of illness, with a fluctuating need for personal assistance. Other patients, who together constitute the largest group of dependent elders, are frail (28%) or have advanced dementia (14%).⁴

Patients with dementia have a limited ability to participate in self-management. If their medical care is to be patient-centered, reflecting the values they no longer have the cognitive capacity to articulate, clinicians must rely on surrogates to guide them. Yet few programs caring for patients with dementia regularly incorporate caregivers in every phase of care. Most interven-

tions involving caregivers focus on psychosocial support intended to decrease caregiver burden. One of the only studies examining the effectiveness of caregiver education found that patients with dementia whose caregivers were enrolled in a coaching program exhibited fewer behavioral and psychological symptoms than control patients.⁵

Patients with frailty are typically able to express their preferences but often lack executional autonomy: they cannot carry out their wishes without significant assistance. As a result, plans for medical care of frail patients necessitate direct, ongoing involvement of caregivers. Such plans include strategies for following clinical practice guidelines, for example to optimize treatment of diabetes or heart failure, and transitional care intended to avoid readmission after hospital discharge. Few programs targeted to the chronically ill systematically involve caregivers, although those that do have demonstrated beneficial effects on the quality of care. "Guided care," for example, offers comprehensive care to patients with multiple chronic illnesses, using nurse practitioners to perform home-based geriatric assessments and to educate caregivers. A cluster randomized study found that guided care decreased costs and increased patient satisfaction compared with conventional care.⁶

What Is the Role of the Caregiver?

Implementing patient-centered care is a multistage process, and caregivers need to be integrated into each stage. The first step is to ensure that the caregiver, along with the patient, understands the patient's underlying health status. Health status refers to the diagnosis and prognosis, both in the limited sense of life expectancy and also in the sense of the expected trajectory over the coming months or years. This type of understanding is key to realistic decision making. Knowledge that a patient has moderate dementia today but will lose the ability to feed himself or herself and to communicate with family over the next few years may influence choices such as life-prolonging vs comfort-oriented treatment for a new cancer diagnosis. Understanding the vulnerability of the frail person in the setting of a new stressor is crucial to making informed decisions about hospital vs home care of problems such as acute infection.

The second step in achieving patient centeredness is to elicit and prioritize goals of care. Physicians and policy makers alike increasingly recognize the importance of determining the patient's goals as a prelude to planning for future care.⁷ When offered a range of possible goals, many patients indicate that their paramount concern is maximizing quality of life, rather than

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either life prolongation or comfort.⁸ For patients who can participate, caregivers must understand the goals if they are to carry out the patient's wishes in the future. For patients who cannot engage in this process, caregivers must do so on their behalf. Sometimes living wills or other advance directives are available to aid in the process, but such documents, even when available, may be too vague to guide decision making.⁹

The third step involves designing a plan of care. The patient's goals are the basis on which a plan of care should be constructed but are not sufficient for clinicians or caregivers to know exactly what to do when problems develop. Translating a patient's goals into practice requires determining what interventions are appropriate: a patient with dementia and a myocardial infarction whose primary goal is to maintain independence is probably a candidate for placement of a coronary artery stent but not for coronary artery bypass graft surgery, which would likely necessitate a prolonged course of rehabilitation and perhaps a further loss of function.

Generating a plan of care also requires a comprehensive assessment of both the patient and the patient's surroundings. Whether the patient with advanced illness who develops pneumonia can be treated at home or will require hospitalization depends on the availability of a personal caregiver and a safe physical environment. The care plan must specify what the response should be when foreseeable problems develop—for example, when the patient with advanced congestive heart failure has an exacerbation or the patient with chronic obstructive pulmonary disease develops bronchitis.

Specifying exactly what should happen in all possible circumstances is impossible, but the plan should be sufficiently precise to guide the patient, caregiver, visiting nurse, emergency department physician, or primary care physician.

Care plans need to be available across the sites of care. In the complex US health care system, in which patients are cared for in the home, the physician's office, the hospital, and the skilled nursing facility, the most carefully thought-out plan of care will prove useless unless its details can be transmitted across sites. Theoretically, this goal can be achieved through an electronic medical record, but not all physicians and hospitals use an electronic medical record, and interoperability is not the norm. Over the long run, detailed, written plans of care should be accessible to authorized clinicians via the Internet, but at present direct, personal, explicit communication of the plan by the caregiver is the best guarantee of success.

Implications for the Health Care System

For caregivers to make patient-centered care a reality for frail elders and those with advanced illness, they will need unprecedented education and assistance. In addition to supporting policies designed to reimburse caregivers for some of their services—proposals unlikely to be enacted, given the current political climate—the medical establishment needs to incorporate caregivers at every step of patient care. This will entail a fundamental shift from individual autonomy to family- and caregiver-centered care.

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