

Letters

Invited Commentary

Family Caregivers Needed—No Training Provided

Each year, millions of people in the United States provide care for an older family member with physical or cognitive limitations. As the population ages, the demand for family caregivers will continue to increase.¹ Often overlooked by the health care system, family caregivers support older adults' health and provide enormous financial and societal value by allowing the deferral or avoidance of institutional care.²



Related article

However, caregivers' responsibilities can be taxing. Consider an example of a patient and her daughter, who was also her primary caregiver. The patient had dementia, severe hearing loss, diabetes mellitus controlled with diet, and a permanent colostomy. As the patient's dementia progressed, the daughter managed her finances, coordinated medical care, provided meals, and ensured her safety. Eventually, colostomy care fell to the daughter as well; the difficulty of this task led to referral to an ostomy nurse who provided appropriate training. When the patient was hospitalized for a urinary tract infection, her diabetes was uncontrolled and she was discharged with instructions to check her blood glucose level 4 times daily. This new responsibility was more distressing to her daughter than colostomy care. She felt unprepared for this role, which in turn triggered her mother's agitation. If her daughter had received appropriate training, their distress might have been avoided.

In this issue of *JAMA Internal Medicine*, Burgdorf and colleagues³ demonstrate how common such experiences are, showing that family caregivers are often undertrained. Using nationally representative 2015 data about family and unpaid caregivers who provide help with personal, mobility, or household activities to community-dwelling Medicare beneficiaries, they found that only 7.3% of caregivers reported receiving any training related to this role. These results point to a profound deficit in caregiver support and training, which can improve health outcomes for both caregivers and recipients of care.²

The timing of caregiver assessment and training is not straightforward. Responsibilities can develop gradually or abruptly, and the required technical expertise can vary widely. After an acute medical event, family members may become caregivers overnight with little time for assessment and training. In contrast, those providing care to individuals with slowly progressive conditions often have responsibilities that increase insidiously over time; despite substantial caregiver stress, the training needs in these situations may not be apparent. Caregivers may also have responsibilities that increase gradually but intensify with acute events that often require learning new skills, as in the case above. Indeed, caregivers are increasingly expected to perform medically intensive

and stressful tasks, such as managing multiple medications, peripherally inserted central catheters, feeding tubes, or surgical drains as well as providing ostomy or wound care.⁴

Although hospital discharge can be especially harrowing for caregivers, it provides a natural opportunity for assessment and referral to training. It is encouraging that Burgdorf et al³ found that recent hospitalization was independently associated with receipt of training. Of note, since 2014, 40 states have passed CARE legislation (Caregiver Advise, Record, Enable), which requires hospitals to provide caregiver support at the time of discharge.⁵

Although clinicians frequently meet with and advise family caregivers, evidence-based recommendations for caregiver assessment are lacking.⁶ To support family caregivers, assessment and training should begin when a patient is initially diagnosed with a chronic illness and be repeated if and when the disease substantially progresses. Recently, Medicare has added reimbursement codes that include mandatory caregiver elements: 2 Transitional Care Management codes for outpatient visits within 7 or 14 days of a patient's transfer from an acute setting back to the community and a Cognitive Assessment and Care Plan Services code for patients with dementia, which can be billed biannually. Further reimbursement for direct caregiver services may follow from the 2018 RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act. Although yet to be fully implemented, this federal law requires the US Department of Health and Human Services to develop, maintain, and update an integrated strategy to support family caregivers.⁷

As the number of older people in the United States continues to increase, failure to address the needs of family caregivers is likely to have far-reaching consequences for the structure and cost of health care. In turn, holding ourselves as a society accountable for supporting family caregivers, including providing appropriate training, is an essential step toward providing comprehensive and high-quality care to older adults. The study by Burgdorf et al³ suggests that our society and health care system have a long way to go to support the valuable, largely invisible, and often overlooked caregiver workforce.

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