INFLUENCING SUPPORT FOR CAREGIVERS

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THE U.S. CENSUS BUREAU estimates that between 2000 and 2030, the population of people ages 65 and older will more than double, from 35 million to 71 million (U.S. Census Bureau, 2004). Census Bureau projections show that the population of people ages 85 and older, the fastest-growing group in the nation, will increase by 126% in the same period, going from 4.2 million to 9.6 million. More people of all ages are living longer with chronic conditions such as cancer, cardiovascular disease, and diabetes, and the prevalence of chronic conditions increases with age (Collins et al., 2005). Increasingly, those facing chronic disease or disability prefer to age in place—that is, to remain independent and in their own homes and communities for as long as possible.

Third-party payors continue to pressure providers to reduce costs associated with inpatient hospital stays and institutional care. In 2000, Medicare's implementation of the prospective payment system for home health care reduced the overall volume of Medicare-financed home health services and shifted the mix of services toward skilled care and away from the long-term support provided by paraprofessionals (Murtaugh et al., 2003). At the same time, federal- and state-level Medicaid officials rebalanced their long-term care strategies to emphasize home- and community-based rather than facility-based care. In 2000, an estimated 83% of people with long-term care needs lived in the community and more than half were 65 years old or older, according to the Georgetown University Health Policy Institute's analysis of data from the National Health Interview Survey (Rogers & Komisar, 2003). This percentage will only grow as Medicaid, the primary payor for long-term care, continues to shift funding away from institutional care and as people ages 65 and older constitute more of the total population.

Health care providers, including all individuals and institutions that deliver medical care to patients, must also face the anticipated shortage of health care workers, especially when projecting long-term care needs. Auerbach and colleagues predict an overall shortfall of 340,000 RNs by 2020, and RNs in long-term care settings currently represent

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only a small percent of the total RN workforce (Auerbach et al., 2007). At the same time, providers are already having difficulty attracting and retaining enough paraprofessional direct care workers because of low wages, unpredictable work hours, and the lack of benefits and career advancement opportunities. Friedland calculated that to maintain the current ratio of long-term care workers to the population ages 85 or older, the number of workers would need to "more than double between 2000 and 2050," or grow, at a minimum, by more than 2% per year during this period (Friedland, 2004). He concluded that this growth rate was unlikely, based on his estimation (using data from the U.S. Census Bureau) that the corresponding annual growth in the working-age population would be only 0.3% in the same period.

Many health economists, providers, and policymakers agree that a mismatch exists between how the current health care system defines and pays for services and how care is actually being delivered. Third-party payors and providers view health care as time limited, discrete, and necessitated by acute or catastrophic illness, rather than as long-term, continuous, and provided to prevent the need for more costly care. This places additional pressure on friends and family to provide care after the formal system stops, especially when managing disabilities and chronic conditions. Such care is frequently provided in part or in full by family caregivers. According to Stone, 95% of noninstitutionalized older adults with disabilities receive some assistance from friends and family, and 67% rely on this form of care alone, primarily from wives or daughters (Stone, 2000). But most payors and providers don't acknowledge that family caregivers are an extension of the care delivery team and may need care themselves.

These trends imply that more responsibility for managing both acute (posthospital) and ongoing health care needs will be placed on the shoulders of patients and their families and friends, and that the demand for home- and community-based care, often provided by family caregivers, will increase. However, the supply of such caregivers is shrinking as more women enter the workforce, birth rates decrease (resulting in fewer children to provide care), and the geographic distance between family members grows.

This article describes the challenges faced by providers in integrating and effectively using caregivers and suggests longer-range public policy approaches to address these challenges and spur system changes that respond to caregivers' needs and help them manage the demands placed upon them. A policy agenda for incorporating and supporting caregivers as part of the health care team should be organized around establishing the value of caregivers, establishing standards and guidelines, creating a system of accountability and incentives for providers, and finding a role for technology in helping to incorporate caregivers into the health care team and support their needs.

Establishing the Value of Caregivers

Caregivers provide care that is generally believed to be of high quality, to cost less, and to be consistent with patient preferences. Caregivers perform tasks that range from coordinating care and assisting with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) to administering medications, providing emotional support, and serving as liaisons and translators (Coleman, 2003; Donelan, 2002).

Poorly planned hospital discharge is associated with adverse events, which occur in nearly one in five patients and can precipitate readmission (Forster et al., 2003). Coleman and colleagues reported from previously published sources that national 30-day readmission rates among older Medicare beneficiaries range from 15% to 25% (Coleman et al., 2006). Educated caregivers who are part of the health care team can influence patient outcomes by helping to prevent adverse events. Caregivers can help reduce overall health care costs if their care helps patients avoid unnecessary hospital and ED visits and if caregivers are cared for so that associated health problems they may suffer themselves don't add costs to the system. Other studies have found that caregiving reduces or delays nursing home placement (Lo Sasso & Johnson, 2002; Van Houtven & Norton, 2008). Caregivers also help to connect the components of a fragmented and disjointed system by fostering communication between patients and providers about symptoms, concerns, and recommended courses of action, especially for patients who receive care in multiple settings.

However, more reliable data are needed about the number of caregivers and the costs and effects associated with the care they provide. Estimates of the size of the informal caregiving "workforce" vary widely depending on each study's definitions of *caregiver* and *assistance,* age criteria, and survey methods. Using findings from five studies, AARP estimated that in November 2006, between 30 million and 38 million adult caregivers provided an average of 21 hours of care a week to adults with an ADL or IADL constraint. The estimated value of this care was about $350 billion per year (Gibson & Houser, 2007).

These are indirect estimates. Collecting caregiver data through the U.S. Census Bureau and the American Community Survey—an annual survey by the Census Bureau of 3 million housing units randomly selected from all counties in the United States—would help to establish baseline statistics and annual changes and projections. Standard definitions of family caregiving and reliable estimates of its size and scope could provide strong evidence for the argument that family caregivers provide substantial value to the health care system. Robust estimates of the financial value of the care they provide would build a stronger body of evidence for models that, ideally, would lower costs and improve outcomes. Those models should then be tested and disseminated on a wide scale.

Establishing Standards and Guidelines

National standards and guidelines for transitioning patients from the formal to the informal care system, and particularly for assessing caregiver readiness, training, and ongoing support, need to be established before caregivers can be successfully incorporated into the health care team. These standards can be shaped around promising models that systematically incorporate family and friends into the unit of care. Right now, individuals suddenly "become" caregivers and are provided with little guidance before assuming care responsibilities, yet they are responsible for increasingly complex tasks, including not only clinical tasks, such as wound care, but also symptom recognition and management. A caregiver's ability to recognize a sign of deterioration as an event that requires medical attention could decrease avoidable hospital and ED visits. The earlier and more accurately a caregiver can identify various symptoms, the earlier the caregiver can get the patient to a physician to avert a true emergency, but only a few interventions designed to improve caregiver training, well-being, and ability to take action have been rigorously tested. Such interventions appear to have a considerable effect on measures such as the rehospitalization rate and patient and caregiver satisfaction (Coleman et al., 2006). However, these interventions have yet to be nationally disseminated and adopted. Third-party payors understandably hesitate to reimburse providers for caregiver training without having a larger body of convincing and credible evidence of the benefits, and providers have no financial incentive to invest time in educating caregivers during routine patient encounters if they depend on volume and staff productivity for their fiscal health.

Hospice care could provide a model for formally incorporating family caregivers. In hospice care, family caregivers are considered care recipients as well as part of the health care team. They receive counseling throughout the period of patient care along with training to manage and recognize symptoms to ensure good palliative care. However, the philosophy of hospice care differs considerably from that of acute and postacute care. Hospice care, by definition, includes a patient's family in the unit of care, and all hospice clinicians and staff are so oriented. Home-based hospice care models support the family caregiver to enable the patient to remain at home. This includes preparing the caregiver from the start of care for dealing with practical matters—such as how to position a care recipient in bed, transfer her or him between bed and commode, and provide care to maintain comfort—and reinforcing that preparation during every nursing visit to the home. It also includes preparing the caregiver for what to expect when a person is dying. The Medicare hospice benefit supports the family caregiver by paying for an integrated package of medical and social services, including bereavement services and clinical staff who are accessible around the clock if needed. Staff can spend the time required to educate and support caregivers, in addition to providing palliative care to patients. Arguably, the process reduces staff productivity because more time is required per encounter. The resource-intensive hospice care model could be difficult to follow for organizations that have sizeable patient volumes.

Creating a System of Accountability and Incentives

Once standards and guidelines are established, providers should be held accountable for educating, training, and supporting caregivers as partners in care. Incentives for involving caregivers, and disincentives for not involving them, need to be substantial enough to motivate *providers* to do so. Providers could be held accountable if accrediting agencies such as the Joint Commission and the Community Health Accreditation Program required them to involve and train caregivers as part of the accreditation process. Once experience demonstrates that educated caregiver involvement can improve rehospitalization rates and patient and family satisfaction while reducing avoidable errors, adverse patient outcomes, and subsequent litigation, senior leadership in health care organizations will be motivated to exert their influence and disseminate the evidence.

Even with solid evidence about associated savings and benefits to patients, providers are unlikely to absorb the costs of involving and training caregivers without assurance that third-party payors will reimburse them for this investment. A logical place to begin advocating for payment reform is at the state level, where Medicaid budgets are administered. Medicaid's role is to ensure that low-income Americans have access to health care. In addition, though, it serves as the long-term care safety net for people who have depleted personal assets. Medicaid currently pays for 42% of U.S. long-term care expenditures, with more than half of its long-term care recipients being age 65 or older (Kasper et al., 2007). However, the majority of Medicaid long-term care dollars still go toward nursing home care, and the functional and financial limitations required to access long-term health care provided in noninstitutional community settings are more stringent than for nursing home care. This effectively restricts the home health aide services that are available to community-dwelling Medicaid enrollees and increases the long-term-care burden on family caregivers. Rebalancing Medicaid away from institutional care at the state level would allow more people access to home-based long-term care services and at least somewhat decrease the burden on their unpaid caregivers. States also have the leeway to include caregiver training in the standard 1915(c) waiver programs that are submitted to the Centers for Medicare and Medicaid Services for federal approval. States should be strongly encouraged to design and implement rigorous demonstration projects to show that investment in caregiver assessment, training, and support pay off in future savings.

Making the Case for Technology

Technology has the potential to extend the reach of caregivers, decreasing the number of hours of personal assistance a care recipient needs and providing some respite to caregivers. It can bridge geographic distance between providers, caregivers, and patients, such as those in rural areas. Assistive technologies (items, equipment, or systems that maintain or improve the functional capabilities of disabled individuals) can reduce the reliance on personal caregivers to safely carry out ADLs and IADLs. Technology can also provide regular and *reliable* monitoring of safety, symptoms, and treatment adherence, thus improving outcomes. Such technologies include remote motion sensors placed around the home that can turn on a light or detect unusual movement patterns that might signal the occurrence of an event that requires follow-up and medication dispensers that store multiple prescriptions and alert the care recipient when it's time to take a particular medication or even sense when the dispenser is opened. Such devices can be very helpful for caregivers who are monitoring a patient's adherence to what is often a complicated medication regimen.

Technology can also be used to educate, enable, and engage family caregivers. For example, multiple companies are developing or have developed electronic personal health records that allow patients and their delegates to access health information via a Web portal. The usefulness of such portals to patients has been discussed, but these benefits apply equally to family caregivers. Some portals offer process-related functions, such as the ability to view and modify appointment schedules, request prescription refills, and communicate with a clinician about nonemergent concerns. Others also combine the personal health information with specific, customized educational self-management tools. All these functions could engage patients and their families, help them communicate effectively with providers, and allow them to better manage health conditions—as long as the technology is intuitive or easy to learn.

These technologic tools require both upfront and ongoing investment capital from providers. A return on investment can be difficult to estimate accurately. It may even be negative because more technologically advanced methods of care may be more costly, though they may improve patient outcomes significantly, reduce errors, and help to deploy an organization's job roles more efficiently and effectively. For example, providing home health care nurses with laptops with wireless access to a central patient database and electronic records requires a considerable investment in equipment and training, but it would also simplify documentation and administrative duties, increasing the time available for clinical management and appointments and potentially improving nursing productivity and patient outcomes. Federal and state governments need to provide more support for the development, evaluation, and spread of technologies that further patient independence and educate, engage, and empower patients and families.

Considerations for the Future

In the future, the demand for family caregivers will likely outpace the supply. While no single solution will address this gap, better support for caregivers can help to mitigate the potentially dire effects of the gap on both patient outcomes and health care costs. The value of family caregivers and their quantifiable effect on costs and outcomes need to be established. National standards and guidelines for transitions between formal and informal care systems—and especially on assessing caregiver preparedness and providing necessary training—should be developed, followed by a means for measuring performance and holding providers accountable for assessing and preparing caregivers. Providers should be encouraged to adopt technologies that hold promise for extending their reach, for engaging and educating patients and their families in self-managing conditions, and for transforming how ongoing care is delivered.

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