

Informal Caregiving

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Informal caregiving refers to the help and support that unpaid caregivers, usually family members and friends, provide to assist individuals who are unable to function independently. Caregiving involves a wide range of tasks, such as help with activities of daily living (ADLs, e.g., eating, bathing, dressing, getting into or out of a bed or chair, using the toilet) and instrumental activities of daily living (IADLs, e.g., preparing meals, managing money, shopping, doing housework, using a telephone), assistance with medications and doctor's visit, and providing emotional support.¹ In 2009, approximately 65.7 million people (or 29% of the U.S. population) provided unpaid care for a chronically ill, disabled or aged family member or friend in the last twelve months, according to the National Alliance for Caregiving and AARP survey.² On average caregivers spent 20.4 hours per week providing care and some caregivers have a greater caregiving burden than others. For example, for those who live with their care recipients, caregiving is particularly time-intensive (39.3 hours per week), and these caregivers also have been in their role longer, on average 6.5 compared to 3.8 years for those who live separately.²

The economic value of informal caregiving is substantial, estimated at \$375 billion a year,³ with a large majority of caregivers providing care for an older adult. In 2009, seven in ten caregivers take care of someone 50 years of age or older.² As the baby boomer generation ages, the number of people in need for informal care (such as those with AD/dementia) and the resulting economic burden will likely increase. Therefore, family members and other informal caregivers may face greater challenges mentally, physically, and financially in the coming decades. The topics discussed below are some gaps in the knowledge base and recommended "next steps" for research.

Projected economic value of informal caregiving

Several studies have estimated the number of caregivers providing personal assistance to adults and the average caregiving hours based on nationally representative surveys.⁴ To estimate the economic value of informal caregiving, existing studies generally apply a market wage rate to caregiving activity.^{4,5} However, several issues related to the costs of caregiving to caregivers and to society warrant further examination. For example, what is the economic impact of providing informal care on caregivers' health care utilization? How much do caregivers pay out-of-pocket for the care recipient's health needs? What approaches may be employed to better quantify productivity loss and loss of income as well as other benefits arising from informal caregiving (for example, when a caregiver gives up a job or reduces work hours)?⁵

In addition, future costs of informal caregiving are largely understudied. What will be the projected costs given aging of the Baby Boom generation? How will growing demands for informal caregiving impact future health expenditures for home health and nursing home care? What are the implications

for Medicare and Medicaid programs? Research that aims to develop, test, and/or refine existing methods is also needed to better estimate the current and future economic burden of informal care.

Caregiver burden and health impact on caregivers

Caregiving often entails dealing with multiple concurrent stressful events and can negatively affect caregivers' own physical and mental health.⁶ One study found that spousal caregivers for individuals with AD had higher rates of diabetes, arthritis, ulcers and anemia than the general population.⁷ Spousal caregiving also has been associated with increased risk of coronary heart disease, hypertension, depression, and mortality.⁸⁻¹¹ According to the 2009 Caregiving in the U.S. study, more than half of caregivers consider their caregiving situation to be highly stressful or moderate stressful (53% rating stress 3 to 5 on a 5-point scale).² The longer caregivers have been providing care, the more likely they are to report fair or poor health status.²

Although characteristics of caregivers have been documented at the population level, variation in subgroups is not well understood. According to the 2009 Caregiving in the U.S. study, caregivers are on average 48 years of age, 66% are female, 72% are White, 58% are married, and four in ten have completed college (43%) and have less than \$50,000 in household income (42%).² These characteristics along with other factors such as culture and relationship to the patient may influence the caregiving experience. For example, one study showed that on average female caregivers spent more time providing care than men (21.9 vs. 17.4 hours per week), and were more likely to report declining health as a result of their caregiving (20% vs. 12%).² However, the identification of subgroups at high risk of substantial caregiver burden has yet to be carried out.⁶ Because there exists substantial heterogeneity with respect to caregivers' demographic and socio-economic characteristics (e.g., age, race/ethnicity, education, income) more assessments are needed to clarify the relationship between caregiver burden and caregiver characteristics. It would be useful to identify caregivers at increased risk for health declines, and to assess the degree to which the caregiver's health and quality of life may be affected.⁶ Evidence-based approaches are needed to compare various caregiving protocols/interventions that help maintain or improve caregivers' physical and mental well-being. Special attention should be paid to subgroups with different levels of care burden, socio-economic characteristics, and care recipients' health conditions.

In 2008, two-thirds (or 20.7 million) Medicare beneficiaries had multiple (two or more) chronic conditions (MCC).¹² As the number of older adults with MCC is expected to increase, it is important to identify strategies to reduce caregiver burden and to improve the quality and effectiveness of informal caregiving, such as informal caregiving provided by a spouse who may also have MCCs. Additionally, better data are needed to determine the relationship between caregiver and care recipient's health status. How does having similar conditions or disease experiences impact the caregiver and the care recipient's health outcomes? What factors predict changes in caregivers' physical and mental health and quality of life over time?

Caregiver support

Several reviews have examined evidence-based caregiver interventions (e.g., randomized control trials) for conditions such as AD/dementia, stroke, cancer, and mental illness.¹³⁻¹⁸ Various support strategies,

such as family counseling, social support, skills training, and self-care, have been documented. However, depending on the study design, some caregiver support interventions lack well-defined outcomes and therefore the impacts on caregivers are either not clear or not generalizable.¹⁸ Additionally, the literature on transitions into and out of the caregiving role is relatively sparse.¹⁵ Understanding stage transitions in caregiving may shed light on developing strategies to prevent adverse outcomes later in the caregiving experience.¹⁵ Further, while condition-specific support programs are helpful, they typically do not address issues related to MCCs, such as difficulties following complex treatment regimens and managing multiple competing priorities. Because the majority of older adults have MCCs, future caregiver support interventions should identify and address the challenges of caring for MCC patients.

Caregiver support programs involving technology also need further examination. While technology offers the potential to facilitate some caregiving activities and to improve health outcomes of the care recipients, additional research is needed to understand its clinical and economic implications. The 2009 Caring in the U.S. study reports that nearly half of caregivers have used some sort of technology (e.g., electronic organizer or calendar, emergency response system) in the care of their family members or friends.² For example, telemetry and other monitoring devices have been used with dementia patients to observe their movements and locations.¹⁵ One review of family caregiving of dementia patients suggests additional research such as testing innovative approaches to supporting informal caregivers through monitoring technology and sophisticated communication systems is warranted. These findings also may apply to other disease areas in which in-home technologies could be used to enhance the effectiveness of informal caregiving and to decrease the stress or intensity of caregiving efforts. As decision aids, safety technologies, alert systems, and reminders are being developed, it would be useful to assess their clinical and economic impacts (such as reducing adverse drug events through improved medication management support), as well as impacts on improving caregiver knowledge, social support, and decision-making.

The mechanism through which support strategies are delivered would also benefit from additional research. In general there is insufficient information to understand different preferences caregivers have for receiving information.¹⁹ Future studies should employ evidence-based approaches to eliciting caregiver preferences and examining caregiver-centered outcomes. These findings would help improve effective communication and guide future caregiver support programs that meet the particular needs of caregivers. Further, more data are needed to tailor caregiver support activities in order to improve caregiver abilities, decision-making, and health outcomes.

AD/dementia

AD/dementia is the most frequently studied condition of informal caregiving in the literature as AD/dementia care is the more stressful type of family caregiving.¹⁵ One study suggests that not only do dementia caregivers spend more hours per week providing care than non-dementia caregivers, they also report greater impacts on employment complications, caregiver strain, mental and physical health problems, time for leisure and other family members, and family conflict.²⁰ As the disease progresses, individuals with AD/dementia are more likely to have emotional and behavioral problems as well as psychiatric symptoms. One study found that severity of psychiatric symptoms, behavioral disturbances, and patients' quality of life are the main correlates of caregiver burden.²⁰ Although a number of studies have associated AD/dementia severity with caregiver burden, practical markers for predicting caregiver

morbidity have yet to be identified. Because AD/dementia caregivers are at increased risk for certain health problems (e.g., depression, anxiety), future research should develop strategies for early identification of caregiver burden and examine specific interventions along the disease continuum. It is well recognized that AD/dementia is a slowly progressive degenerative illness that includes a prodementia period (i.e., mild cognitive impairment [MCI]) during which symptoms are mild or barely detectable.²¹ More data are needed to characterize the association between caregiver burden and disease progression from MCI to more advanced stages of AD/dementia. Furthermore, as AD/dementia advances, the time caregivers spend to assist patients with ADLs and IADLs increases, as does caregiver distress and caregiver work time lost, resulting in substantial indirect costs.²² Recent estimates by the Alzheimer's Association reported 17.4 billion hours of unpaid care provided for AD patients in 2011, valued at \$210 billion.²³ In contrast, the economic value of informal care for individuals with MCI is less clear.²² How do caregiver burden and indirect costs change when patients progress from MCI to mild, moderate, and severe AD/dementia? What measures are most sensitive to and predictive of caregiver burden? Research characterizing the type of caregiver support needed in the trajectory of memory, cognitive, and functional decline would also inform future interventions.

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