

# Next Steps for Research on Informal Caregiving

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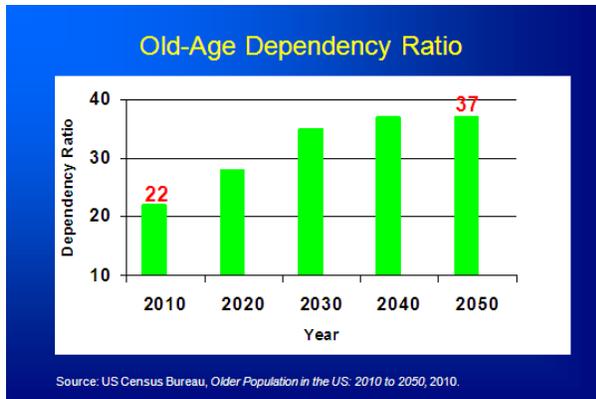
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This review was prepared in response to a request from the National Institute on Aging (NIA) to identify the key “next steps” in research on informal (unpaid) caregiving that would help fill important current gaps in knowledge. Demographic changes underway in the United States make a focus on informal care for the growing number of older adults an especially important topic from scientific, clinical, and public policy perspectives. After reviewing the current literature on informal caregiving, the following topic areas were identified as important areas for future research: 1) The dynamics of family caregiving networks and how they will change with the declining number of adult children per family in the next 40 years; 2) The impact of informal caregiver networks on end-of-life medical care; and 3) Understanding the impact of caregiving on caregiver health, and the future “fitness” of caregivers in the face of increasing rates of childhood obesity and diabetes. Each of these topics is discussed in more detail below.

## **Background**

The key demographic trend that will have the greatest impact on informal caregiving in the next 40 years is the large growth in the number of older adults relative to the “supply” of adult children who will be available to provide informal care. Because growth of the elderly population, especially those aged 85+, will outpace the growth of working-age adults in the United States, the demand for informal care will likely grow significantly (i.e., the number of older adults with limitations in ADLs and IADLs), but the supply of informal caregivers (i.e., adult children aged 20 to 64) will not keep up with the demand. This growing mis-match of informal caregiving demand and supply in the coming 40 years is likely to have major and consequential effects on older adults, families, and public programs (e.g., Medicare, Medicaid, and Social Security).

While the age 65+ population will more than double from about 40 million today to nearly 90 million in 2050, the population age 20 to 64 will only grow by about 27% (from 186 million to 237 million) (US Census Bureau 2010). Hence, the old-age dependency ratio, the number of elderly adults for every 100 working age adults, will increase from 22 today to 37 in 2050 (see figure).



How will families and public programs absorb this large increase in potential demand for informal care? Research that helps answer this question and, therefore, helps to inform policy-makers regarding the health, economic, and public policy impact of these changing demographics should be a priority for future NIA funding on informal care.

### **Priority One: The dynamics of family caregiving networks and how they will change with declining number of adult children in the next 40 years.**

How do families currently divide the “labor” of informal caregiving for older family members in need of daily care? And how will that division of labor change as caregiving duties become more concentrated on the declining number of adult children who will be available to provide care in the coming decades?

A better understanding of a number of specific factors that likely influence which family members provide care, and how much care they each provide, may be especially valuable targets for future research funding in order to improve estimates and projections of the future availability and the societal costs of informal caregiving, including:

- 1) Individual caregiver characteristics—e.g., age, gender, education, marital status, occupation, number of siblings, and whether the child is a step-child;
- 2) Market-level characteristics—e.g., availability of substitutes for informal care, such as home care services, assisted living, and nursing home availability
- 3) Geography—e.g., how does physical distance from the older adult influence the division of caregiving duties across children, and how often do children and/or parents move their residence in response to health changes in the older adult? How will physical distance between parents and children change in the coming decades? How can new technologies—internet, smartphones, Skype, GPS, video monitoring capabilities, health sensors and monitors—be used to “close the distance” between older adults and their caregivers? What are the effects of these new technologies on care recipient and caregiver well-being?

One innovative focus for future research funding would be the identification of the full “potential” caregiving network available to an older adult (e.g., spouse, children, neighbors) before the onset of illness and/or disability, and then following this full caregiving network longitudinally both before and

after the onset of illness / disability in an older adult.<sup>1</sup> There is currently extremely limited information on the characteristics of the potential caregiving network for older adults, the factors associated with how informal caregivers become “nominated” from the pool of potential caregivers, and the key long-term effects of becoming a caregiver on the caregiver’s health and economic (e.g., labor force participation) outcomes. The demographic changes noted above make understanding the composition of caregiving networks and the “bargaining” across member of the network that result in the identification of actual caregivers especially important in the coming decades. The availability of cross-national data on caregiving networks would be especially useful for identifying how differences across countries in social welfare programs, pension programs, and the organization of health care systems might affect the composition and availability of caregiving networks, as well as the outcomes of informal caregiving.

## **Priority Two: The impact of informal caregiver networks on end-of-life medical care**

A significant portion of medical expenses are incurred in the last 6 months of life, and the intensity and cost of end-of-life (EOL) medical care varies significantly across different geographic regions of the country (Dartmouth Atlas of Healthcare, 2012). There is currently limited information on how the informal caregiver network that supports an older adult near the end of life influences the quantity and quality of the care received. In addition, there is very limited information regarding the impact of the informal caregiver network on the quality of communication between an older patient and his/her physicians or other health care providers and, in turn, the likelihood that an older patient will receive EOL care that is aligned with their preferences for care (Wolff 2012). Given the large share of health care expenditures that are incurred at the end of life, research that better identifies how older patients’ informal caregivers and support network influences the quantity and quality of EOL care would be extremely valuable to patients, families, and policy-makers in the coming decades.

A number of recent studies underline the importance of better understanding patient and family decision-making at the end of life and perhaps provide some specific aspects of EOL care that may be especially valuable as future targets for research funding. For instance, Silveira and colleagues used the Health and Retirement Study (HRS) to study decision-making at the end of life and how advance directives (i.e., living wills and durable powers of attorney for health care) may affect the EOL care received. They found that more than 25% of older adults who died between 2000 and 2006 in the US needed health care decisions to be made in the final days of life, but were too cognitively impaired to make those decisions (Silveira et al, 2010). The fact that more than 1 in 4 older adults will not have the capacity to make their own decisions on care at the end of life emphasizes the importance of better understanding how informal caregivers interact with the health care system when an older adult is seriously ill, and how that caregiver network ultimately affects the decisions being made.

Research on the impact of advance directives on EOL medical care and costs has been quite mixed over the last twenty years, with some studies finding no impact of advance directives on the intensity and cost of EOL care and other studies finding an impact. A recent study on the impact of advance directives on EOL care may help explain the mixed results of prior studies. Nicholas and colleagues used HRS data to show that patients with advance directives who lived in areas of the country characterized by high-

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<sup>1</sup> The potential value of prospective identification of a caregiver network was discussed by John Phillips and Jonathan King at the Health and Retirement Study (HRS) Data Monitoring Committee Meeting, Bethesda, MD, September 7<sup>th</sup>, 2012.

intensity EOL care received less costly care in the last 6 months of life compared to patients without advance directives, but there was no difference in the cost of EOL care for those with and without advance directives in areas of the country characterized by moderate- and low-intensity care (Nicholas et al, 2011). In other words, the impact of advance directives on the care received may depend on the “baseline” level of care in a geographic region. This geographic variation in the impact of advance directives on EOL care may provide an excellent research opportunity to better understand how families and informal caregivers affect EOL care. Is the different impact of advance directives on EOL care in different regions of the country due, in part, to differences in how families and informal caregivers interact with the health care system in these different regions? Future research in this area, given the high cost of EOL care, could be extremely useful.

Another potential area for improvement in EOL care is reducing burdensome transfers from nursing homes to hospitals in older patients with severe cognitive or functional impairment who are unlikely to gain benefit from these transfers. A recent study found that 19% of nursing home decedents with severe cognitive impairment between 2000 and 2007 had at least one burdensome transfer, defined as a transfer occurring in the last 3 days of life, a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or if there were multiple hospitalizations in the last 90 days of life (Gozalo et al, 2011). As with other EOL care, the likelihood of burdensome transfers varied significantly across geographic regions from a low of 2.1% of decedents in Alaska to 37.5% in Louisiana. Patients with a written advance directive had a lower likelihood of having a burdensome transition. This study was not able to address how the family and informal caregiver network might affect the risk for burdensome transitions among older nursing home residents, which is an important gap in our current understanding of determinants of EOL care that is likely leading to poorer outcomes and higher costs.

In summary, key research questions regarding the impact of patients’ informal caregiving network on EOL care include:

- 1) Does the size and characteristics of an older adult’s informal caregiving network have a significant impact on the intensity and quality of EOL care?
- 2) How can communication between informal caregivers and health care providers be structured to improve outcomes and ensure that EOL care is aligned with patients’ preferences?
- 3) Can certain types of informal caregiver networks increase the likelihood that patients will use advance directives, and these advance directives will, in turn, increase the likelihood of EOL care that is aligned with patients’ preferences?
- 4) Can informal caregiver networks help decrease burdensome transitions among nursing home residents with severe cognitive impairment? If so, how do these networks lead to fewer burdensome transitions?

### **Priority Three: Understanding the impact of caregiving on caregiver health, and the future “fitness” of caregivers in the face of increasing rates of obesity and diabetes**

How does providing informal care affect a caregiver’s health? A significant body of research has examined the health effects of caregiving (Schulz et al, 1997), especially among caregivers for elderly individuals with dementia (Schulz et al, 1995). The negative health effects that have been shown associated with dementia caregiving include increased rates of depression and anxiety, and poorer self-rated health status (Ory et al, 2000). These negative health effects may be due, in part, to poorer health behaviors (less physical activity, sleep, and rest) among dementia caregivers (Ory et al, 2000). Schulz and colleagues have shown that individuals who reported physical or emotional "strain" associated with their caregiving had significantly higher rates of mortality over four years of follow-up (Schulz et al, 1999)

In contrast to this research showing significant negative health effects of caregiving, a number of studies have found evidence for beneficial physical and mental health effects associated with caregiving (Brown et al, 2003; Brown et al, 2009; Fredman et al, 2011; Bertrand et al, 2012). Potential explanations for these positive health effects of caregiving include stress reduction resulting from mutual affection, interdependence, and companionship which may protect individuals against the adverse consequences of caregiving. Some evidence suggests that high SES caregivers are more likely to realize sustained mental health benefits than low SES caregivers, perhaps due to comparatively better social skills and less stressful home environments (Krause et al, 2000).

Given the conflicting results of much prior research on the health effects of caregiving, future studies using representative samples of caregivers who are providing varying levels of care are necessary to better identify those factors that are associated with negative health outcomes, so that caregiver interventions can be effectively targeted. In addition, longitudinal studies examining how the process of caring for an older adult evolves over time (as noted above) would provide important new information on the causes and mechanisms for both positive and negative outcomes in caregivers.

Separate from the issue of the effect of caregiving on a caregiver’s health is whether important general secular trends in health and disability will result in a pool of future caregivers that will be less able to provide care to the growing number of older adults due to their own poor health. While there has been a significant and sustained decline in levels of disability among older adults over the last 30 years, recent evidence suggests that disability levels may now be increasing among middle-aged adults (Martin et al, 2010). For instance, Martin and colleagues recently used data from the National Health Interview Survey to track mobility limitations among those aged 50 to 64 and found a significant increase in limitations between 1997 and 2007 (Martin et al, 2010). Increasing rates of diabetes and obesity were identified as likely causes for this worsening trend in health and function among middle-aged adults. Given the recent large increase in rates of childhood obesity and diabetes, it is possible that the future pool of caregivers may not be physically able to provide the same level of care to older adults as present-day caregivers. Future research to track these trends in disability, both among older adults as well as middle-aged adults will be important for forecasting the “supply” of informal care that will be available to older adults in the coming decades.

## References

1. Beach S, Schulz R, Yee J, Jackson S. Negative and positive health effects of caring for a disabled spouse: longitudinal findings from the caregiver health effects study. *Psychol Aging*. 2000; 15:259-271.
2. Bertrand R, Saczynski J, Mezzacappa C, Hulse M, Ensrud K, Fredman L. Caregiving and cognitive function in older women: Evidence for the Health Caregiver Hypothesis. *J. of Aging and Health*. 2012; 24(1): 48-66.
3. Brown S, Nesse R, Vinokur A, Smith D. Providing social support may be more beneficial than receiving it: Results from a prospective study of mortality. *Psychological Science*. 2003; 14(4): 320-327.
4. Brown S, Smith D, Schulz R, Yee J, Ubel P, Kabeto M, Kim C, Langa KM. The health benefits of caring for your spouse: Caregiving and decreased mortality in a national sample of older adults. *Psychological Science*. 2009; 20(4): 488-494.
5. Burton L, Newsom J, Schulz R, Hirsch C, German P. Preventative health behaviors among spousal caregivers. *Preventative Medicine*. 1997; 26:162-169.
6. Dartmouth Atlas of Healthcare. *End of Life Care*. Available at: <http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=18>
7. Fredman L, Cauley J, Hochberg M, Ensrud K, Doros G. Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of Caregiver-Study of Osteoporotic Fractures. *JAGS*. 2010; 58(5): 937-943.
8. Gozalo P, Teno J, Mitchell S, Skinner J, Bynum J, Tyler D, Mor V. End-of-life transitions among nursing home residents with cognitive issues. *New England Journal of Medicine*. 2011; 365(13): 1212-1221.
9. Krause N, Shaw BA. Giving social support to others, socioeconomic status, and changes in self-esteem in late life. *J Gerontol B Psychol Sci Soc Sci*. 2000; 55:S323-S333.
10. Martin L, Schoeni R, Andreski P. Trends in health of older adults in the US: Past, present, future. *Demography*. 2010; 47: S17-S40.
11. Martin L, Freedman V, Schoeni R, Andreski P. Trends in disability and related chronic conditions among people ages fifty to sixty-four. *Health Affairs*. 2010; 29(4): 725-731.
12. Nicholas L, Langa KM, Iwashyna T, Weir D. Regional variation in the association between advance directives and end-of-life Medicare expenditures. *JAMA*. 2011; 306(13): 1447-1453.
13. Ory M, Lee J, Tennstedt S, Schulz R: The extent and impact of dementia care: unique challenges experienced by family caregivers, in Schulz R (ed): *Handbook on Dementia Caregiving*. New York, Springer; 2000:1-32.
14. Schulz R, Newsom J, Mittelmark M, Burton L, Hirsch C, Jackson S. Health effects of caregiving: the caregiver health effects study: an ancillary study of the cardiovascular health study. *Ann Behav Med*. 1997; 19:110-116.
15. Schulz R, O'Brien AT, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence correlates, and causes. *Gerontologist*. 1995;35:771-791.
16. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the caregiver health effects study. *JAMA*. 1999; 262:2215-2219.
17. Silveira M, Kim S, Langa KM. Advance directives and outcomes of surrogate decision making before death. *New England Journal of Medicine*. 2010; 362(13): 1211-1218.
18. US Census Bureau. 2010. [The Next Four Decades: The Older Population in the United States: 2010 to 2050](http://www.census.gov/prod/2010pubs/p25-1138.pdf). Available at: <http://www.census.gov/prod/2010pubs/p25-1138.pdf> .
19. Wolff J. Family matters in health care delivery. *JAMA*. 2012; 308(15): 1529-1530.