

# Next Research Steps in Caregiving

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## **Introduction**

Community-based caregiving of older adults involves care recipients who “age in place” (in their homes or evolving community housing arrangements such as naturally occurring retirement communities) and who rely on services and support provided by caregivers to assure optimal function and quality of life, and to avoid unnecessary use of costly health and long-term services and supports. While multiple sources of community-based caregiving often co-exist and the mix of such services may evolve over time (largely in response to common transitions in care recipients’ or caregivers’ health status), one source is usually dominant at a point in time—either “*informal caregiving*”, provided by families members of all ages, friends and/or community members or “*formal caregiving*”, provided by staff members employed by various community-based agencies. Beyond these common sources, caregiving also is supplied by individuals who are employed directly by families and may not be formally prepared for their respective roles (e.g., recent immigrants).

Given the projected growth of older adults with increasingly complex physical, cognitive, emotional and social support issues in the near term, there is an urgent need to identify the most significant opportunities to accelerate the development and dissemination of new knowledge designed to support traditional and non-traditional caregivers and to enhance their outcomes, as well as the outcomes of the recipients of their care. Addressing this need is challenged by the increasing ethnic and racial diversity of the older adult population and their caregivers, and the shrinking economic resources available to support care both of these groups.

Members of the NewCourtland Center for Transitions and Health at the University of Pennsylvania, School of Nursing contributed recent research reports relevant to community-based caregiving that provided the foundation for analysis and subsequent research recommendations regarding “next steps in caregiving research”. Grounded in a broad-based understanding of extant knowledge related to caregiving and an appreciation of the emerging context of community-based caregiving, the following research priorities are suggested. These priorities share in common a focus on the most complex of elderly care recipients (e.g., those

suffering from cognitive deficits, mental health problems, living in poverty, or unable to speak or read English) and the resulting human, ethical, and economic consequences for an evolving generation of caregivers and society. The research recommendations emphasize opportunities over the next few years to advance research targeting the overall population of care recipients and caregivers as well as important subgroups.

## **Recommended Research Priorities**

### **Conceptual/Methodological Advances in Caregiving Research**

Reported studies examining the effects of caregiving have typically relied on diverse theoretical frameworks and traditional analytical approaches to examine the relationship of a given factor (e.g., ethnicity) to an outcome (e.g., caregiver stress), after adjusting for other variables.<sup>1-2</sup> Although helpful in offering a wide range of possible contributing factors on caregiver outcomes, such largely regression-based studies have not offered an integrated picture of the direct and indirect pathways among an array of factors that impact the health and well-being of caregivers.<sup>3-4</sup> Alternative research designs and analytical lenses are needed to broach the multidimensionality and complexity of caregiving. For instance, multidimensional models based on prior research would enable testing of more robust hypotheses. Such models could explore the combined effects of both formal and informal caregiving on the physical and psychological health of caregivers, taking into consideration such factors as the needs of care recipients, characteristics of caregivers, and contextual issues such as the socioeconomic status (SES) of families. Simultaneous examination of the relationships between hypothesized constructs using statistical techniques such as structural equation modeling, social network modeling and dyadic analysis could accelerate knowledge about this complex phenomenon. Moderated-mediation analyses may identify how pathways vary for subgroups (e.g., caregivers and recipients from diverse ethnic backgrounds). Longitudinal studies using such models could elucidate the dynamic nature of caregiving along a continuum—the sources of common transitions into different phases and the probable effects (both positive and negative) of such transitions. Additionally, qualitative research is needed to understand the varied experience and meaning of caregiving from a patient and family-centered perspective. Knowledge generated from such frameworks could influence the design and alignment of services to better match caregivers' evolving needs and provide benchmarks of service effectiveness.

## Advances in Understanding the “Unexamined” Informal Caregivers

To date, most research has focused on a narrowly defined set of informal caregivers—often a single family member (e.g., spouse or daughter) who assumes primary responsibility for the on-site care of another family member. Advances in science are needed to identify the unique needs and challenges experienced by the more diverse groups of caregivers who have emerged in recent years due to major socio-demographic changes, as well as changes in the needs and characteristics of care recipients.<sup>5</sup> The following groups are illustrative of such “unexamined” informal caregivers.

**Long-Distance Caregivers.** There are an estimated 5-7 million long-distance caregivers in the United States.<sup>6</sup> Long distance caregiving often is needed when employment opportunities require adult family members to be geographically separated from their elderly care recipients. Attempting to care remotely for elderly family members with cognitive, emotional and/or physical deficits results can result in tremendous human and financial burden for all involved. Approximately 70% of working caregivers report stressors causing some to leave their jobs, others to take unpaid leave and the remainder to report job-related difficulties.<sup>7</sup> Remote caregiving has been found to negatively affect productivity of employers.<sup>8</sup> Research is needed to examine the relationship between current economic conditions and long-distance caregiving. In the next few years, studies are needed to: identify factors that contribute to both positive and negative outcomes for long distance caregivers and care recipients; explore how long distance caregiving affects disadvantaged groups (e.g., poor, underserved, immigrants); and test interventions (including technologies) and/or policies (including employer-based incentives) that could advance effective long-distance caregiving.

**Secondary Caregivers.** Research is needed to increase knowledge regarding the roles of all family members, friends, and members of the community who often are major contributors to the caregiving process (via time and support with caregiving tasks, financial and emotional support, etc.).<sup>9</sup> The involvement of these secondary caregivers, who are rarely referenced in the literature, also can complicate this process (due to conflicts about level of engagement, disagreements regarding care plans, etc.). In the short term, gaps in understanding regarding the role and influence of secondary caregivers on outcomes of primary and secondary caregivers and care recipients needs to be addressed, with studies focused on the following: the nature of secondary caregivers and how they facilitate or serve as barriers to the care of older adults with dementia; differences in the use of secondary caregivers for this population of care recipients among diverse subgroups (i.e., the influence of culture, ethnicity and race); the relationship between the use of secondary caregivers for this patient group, and coping abilities of primary caregivers and outcomes of all involved parties; and, the economic effects on society of secondary caregiving among older adults with Alzheimer’s Disease and other dementias.

**“Hidden” Caregivers.** Hidden caregivers include a growing group of individuals who typically are paid by families “under the table” for their work. The growing population of older adults with Alzheimer’s disease or other dementias has contributed to the growth in privately paid home care workers. There are an estimated 2 million home care workers in the United States, including those providing live-in, round-the-clock care.<sup>10</sup> Of these caregivers, more than 500,000 are immigrants and approximately 1 in 5 is undocumented.<sup>11</sup> Often, “hidden” caregivers become intimately connected with families, providing comfort and care for afflicted family members. Unfortunately, many have little or no training in managing the complex needs of older adults with cognitive deficits. Additionally, these caregivers generally have limited proficiency in English which creates huge communication barriers between them, care recipients and other family members and increases the vulnerabilities of all involved parties. Finally, there may be substantial cultural differences between caregivers and care recipients. In the short term, research is needed to better understand the benefits and challenges presented by this growing group of “hidden” caregivers: who are these caregivers; what are effective means of outreach to them and to the families that employ them; and, how can communication barriers (i.e., lack of trust, limited English proficiency, cultural differences) between this group of caregivers and care recipients be effectively addressed.

**Caregivers of Care Recipients with Special Needs.** Recently, we have witnessed changes in both the demography of caregivers (e.g., increased numbers of grandparents caring for developmentally disabled children and increased number of men caregivers) and care recipients (e.g., growing numbers of developmentally disabled adults who are outliving parent caregivers). Research is needed to describe this changing landscape and provide direction for changes in service delivery and policies.

### **Advances in Understanding Formal Caregiving**

To date, studies of formal caregiving have typically focused on the context of care (e.g., hospitals, home healthcare, skilled nursing facilities, palliative and hospice care) from the perspective of the care recipient. With few notable exceptions (e.g., training of professional home health staff), relatively little attention has been paid to formal caregivers.<sup>11</sup> Additionally, most advances in science related to the coordination of care across these contexts, particularly during vulnerable transitions in health and health care, also have targeted care recipients. Finally, there are specific formal contexts of care for which research is lacking. In the near term, research on the following areas could increase our understanding of opportunities to address the needs of formal caregivers.

**Decision Making Regarding Formal Caregivers.** At least part of the challenge in addressing needs of care recipients is determining when formal services are needed (e.g., major transitions in health) and which of the available services are best designed to match older adults’ evolving

needs. The full range of factors that influence such decision making (e.g., access to and quality of available services, SES status of care recipients/caregivers, availability of insurance [Medicare, Medicaid, supplemental and long-term care], and costs of services, and cultural factors, to name a few) needs to be examined.

**The Evolving Community-Based Workforce and the Context of their Work.** In the next few years, increased attention needs to be paid to the unique challenges and training needs of aides or other community health workers who deliver services in older adults' homes or in community-based settings such as adult day care. What are the most effective and efficient strategies to prepare such workers for their roles, promote their integration within the informal care network, prevent common and costly work-related injuries and identify opportunities for performance improvement? What policies are needed to promote retention and more consistent use of a workforce?

**Outcomes of Formal Caregiving.** The impact of formal services should be rigorously studied across settings on outcomes of greatest relevance to *care recipients* (e.g., effective engagement of older adults, care processes such as health behaviors and on outcomes such as health status, perceived quality of life, delays in institutionalization, avoidance of preventable emergency department visits and hospitalizations, a “good death”, overall costs); to *caregivers* (e.g., physical and depressive symptoms, self-care, psychological well-being, quality of life) and to *society* (e.g., robust measures of formal services; overall quality outcomes; differential impact by context and on subgroups; core components, duration and intensity of services needed; and, total costs).<sup>3,12-17</sup>

### **New Foci for Intervention Research**

A robust body of knowledge exists related to the negative health consequences (physical and psychological) associated with caregiver stress and/or burden.<sup>16,18-22</sup> Additionally, rigorously designed studies funded primarily by the National Institute on Aging, for example, have demonstrated the promise of various multidimensional intervention strategies (e.g., REACH II, the NYU Caregiver Intervention, and Savvy Caregiver) in improving the outcomes of informal caregivers of older adults with Alzheimer's disease and other dementias.<sup>18,23</sup> Comparative effectiveness studies are now needed to demonstrate which of these interventions work best, for whom and under what circumstances. Foci for intervention studies designed to improve care both within and across selected formal caregiving contexts and to better integrate formal and informal caregiving also are described below.

**Comparative Effectiveness Research.** An immediate priority should be a “head to head” testing of rigorously studied approaches to identify: which are most effective and efficient in achieving positive impact on *care recipients* (e.g., on care processes such as health behaviors and on

outcomes such as health status, perceived quality of life, delays in institutionalization, avoidance of preventable emergency department visits and hospitalizations, overall costs) and *caregivers* (e.g., physical and depressive symptoms, self-care, psychological well-being, quality of life); how do these effects differ based on relationships between caregivers and care recipients, race, ethnicity, SES status; and, what are the core components of more effective approaches.

**Interventions Designed to Integrate Formal and Informal Caregiving.** Recent studies suggest that almost half of informal caregivers perform medical or nursing tasks for care recipients and most learned to manage these complex tasks on their own.<sup>24</sup> Additionally, as noted earlier, the evolving formal and “hidden” caregiver workforce are being asked to manage similar tasks, often off-site and with limited preparation and, at times, complicated by language, literacy and cultural challenges. To address the complex learning needs of both formal and informal caregivers, and simultaneously promote a more integrated network of formal and informal caregivers, studies of “learning health systems” are needed. Additionally these studies should engage caregivers in the design of studies and the interpretation of findings. An extensive body of literature exists on the importance of informational and supportive services for caregivers.<sup>20-21,25-26</sup> There is existing evidence for the effectiveness of video education,<sup>27</sup> telephonic support,<sup>1-2,28-36</sup> and online support of diverse family caregivers.<sup>37-38</sup> Tests of innovative educational strategies (e.g., alerts, coaching, support networks) available via existing and emerging technologies (e.g., smart phone applications) should be a focus of studies in the next few years.

### **“Cost” of Caregiving**

In general, there is significant need to advance knowledge regarding the economic consequences of caregiving overall, as well as on specific subgroups including women, men, minorities and those living in poverty.<sup>39</sup> For people 50 years of age and older, the total estimate of aggregated lost wages, Social Security benefits and pension associated with caregiving is approximately \$3 trillion.<sup>8</sup> Over the next few years, efforts should focus on establishing a framework for robust economic analyses of the “costs” of caregiving, with particular attention to the economic burden experienced by women.

**Economic Burden of Caregiving Among Women.** Women will account for nearly 50% of the total U.S. labor force in 2018,<sup>40</sup> and, thus, are essential to assure a healthy economy. Available evidence suggests that women tend to leave the workforce rather than reduce hours in order to address caregiving responsibilities.<sup>41</sup> There is little research, however, on whether women understand the long-term economic consequences of their decisions.<sup>42-43</sup> Nor are the long-term health consequences of such decisions on this group of caregivers well-understood. In the short term, research is needed to understand the long-term economic and health-related effects on

women who leave their jobs, reduce work hours or take lower-paying positions to care for parents/family members with Alzheimer's disease or other dementias.

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