

Next Steps for Research on Informal Caregiving

In seeking cutting-edge research directions that can lead to interventions to address the unmet and growing needs of informal caregivers, in 2012, the National Institute on Aging (NIA) commissioned experts in the field to write brief papers about key knowledge gaps and research priorities in informal caregiving. Click on the author's name to go to their paper. Below, is a summary of the key recommendations made in these papers.

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Summary

Guided by the interest in establishing priorities for a research agenda on informal caregiving, in 2012 the National Institute on Aging (NIA) solicited input from experts whose specialty lies in different aspects of informal caregiving, through these commissioned papers. While recommendations reflect the distinct expertise and perspectives of the contributors, as briefly detailed in this summary, several common research priorities emerged from the multitude of ideas presented in these papers: (1) to define informal caregiving and better assess its breadth and scope, (2) to improve estimates of the economic impact of informal caregiving to families and societies, (3) to identify predictors of high-risk caregivers, and (4) to develop effective interventions for informal caregivers.

Defining caregiving: To assess and meet the needs of care recipients, it is of foremost importance that consensus be reached on how to define caregiving. Such a definition must take into account the scope and breadth of caregiving, availability of social and economic resources to caregivers, dynamic changes in caregiving needs that accompany progressive illnesses and diseases, and ethnic and cultural differences in caregiver roles.

Economic impact of informal caregiving to families and societies: At present, the costs of caregiving to caregivers and society are not well understood, primarily because the number of informal caregivers is unknown. To form a coherent picture of how informal caregiving impacts society, and of how demographic changes influence informal caregiving, efforts are needed to assess the incidence and prevalence of caregiving, across social and economic conditions, and to characterize the demographic profile of primary, secondary (e.g. family members, friends, religious congregation members), and hidden caregivers, such as undocumented foreign workers. Cross-national research is needed, with data harmonization efforts with international samples, to show how differences in geography, demographic composition, economic environment, social norms and practices, and social program support affect the costs of caregiving.

Identifying predictors of high-risk caregivers: Family caregivers, who are most often women, are faced with ever-changing and mounting challenges, but it is not well understood how caregiving impacts their health and well-being and why some caregivers thrive in the experience of caregiving, whereas others succumb to caregiver distress and burden and unhealthy outcomes of their own. Multiple characteristics and circumstances of caregivers could independently and jointly affect the relative costs and benefits of informal caregiving. By identifying key predictors of high-risk caregivers, this could inform the design of interventions to promote the health and well-being of informal caregivers, at the community, systemic, or individual level, and maximize healthcare utilization, while reducing the financial toll placed on caregivers and society.

Design of Novel Interventions: The highly variable and ever-changing caregiving needs of individuals suffering from progressive diseases can create much uncertainty for family and other informal caregivers, lead to unhealthy outcomes for both care recipients and caregivers, and place undue economic burden on society. To reduce the burden of caregiving and delay nursing home placement, there is a great need for the development and dissemination of effective evidence-based, in home or community-based, interventions for caregivers and care recipients, and of monitoring, surveillance, and communication technological innovations.