

EXECUTIVE SUMMARY

The National Institute of Nursing Research (NINR) session, titled Research In Informal Caregiving: State of the Science Workgroup Meeting, was convened on July 26-27, 2001, in Bethesda Maryland. Dr. Nell Armstrong, Dr. Patricia A. Grady, and Dr. Karin Helmers presided as chairs.

WORK GROUP MEMBERS PRESENT

Patricia G. Archbold, DNSc, RN, FAAN; Judith C. Barker, PhD; Kathleen C. Buckwalter, PhD, RN, FAAN; Louis Burgio, PhD; Patricia Clark, PhD, RN; Laura N. Gitlin, PhD; Barbara A. Given, PhD, RN, FAAN; Brooke S. Harrow, PhD; Gail Gibson Hunt; Sharon K. Ostwald, PhD, RN; Linda R. Phillips, PhD, RN, FAAN; Sandra J. Fulton Picot, PhD, RN, FAAN; Richard Schulz, PhD; Karen L. Schumacher, PhD; Carol E. Smith, PhD, RN; May L. Wykle, PhD, RN, FAAN, FGSA. Absent but contributing member: Spero M. Manson, PhD

FEDERAL EMPLOYEE WORKGROUP MEMBERS PRESENT

Patricia A. Grady, PhD, RN, FAAN; Nell Armstrong, PhD, RN; Karin Helmers, PhD

MEETING SUMMARY

I. Welcome, Charge to the Workgroup

Dr. Armstrong called the meeting to order and welcomed the participants. Dr. Grady gave opening remarks emphasizing the NINR's mission to support clinical and basic research to develop the knowledge base for care across the lifespan and life course. Dr. Grady also highlighted the objectives for the meeting including: 1) a review of the research in informal caregiving, and 2) identification of research opportunities across the field and with attention to special populations such as the cognitively impaired, the technology-dependent, and diverse populations. She noted that workgroup meetings such as this serve as one source of information for NINR to examine the science in particular areas and to identify directions for future investment in research. Dr. Grady acknowledged the support of the NIH Office of Rare Diseases for the meeting.

II. Introduction

Informal caregiving by family and friends is prevalent in the United States and the need for caregivers will increase with the aging population and the health care system trend toward non-institutionalized care. According to a survey conducted by the National Alliance for Caregiving/American Association of Retired Persons National Caregiver Survey (NAC/AARP), more than 22 million adults are informal caregivers to Americans over the age of 50 and 80 percent of those caregivers are family members. There are numerous factors leading to the need for informal care. Chronic illness, for example, is a major source of morbidity, disability, and mortality in the United States and affects more than 100 million people. Those over the age of 65 often suffer from two to four or more chronic illnesses that cause limitations in functional ability and poor health. In addition, it is estimated that approximately 1.5 million children and adolescents have a serious health condition requiring caregiving assistance; 4.1 million adults aged 21 to 64 need personal assistance with some aspect of daily living; 6.8 million persons aged 65 and over have mobility or self-care limitations; and over 30 million persons of all ages are discharged from hospitals each year who need post-acute care assistance.

The majority of home care is provided by informal caregivers, which refers to unpaid family members, neighbors, or friends. It has been estimated that only 14% of home care is provided by formal caregivers or paid providers. Most of the caregivers surveyed by the NAC/AARP were middle-aged, married women who were employed. More than 40 percent of the women caregivers had children to care for as well. Approximately 20 to 30 percent of caregivers regard caregiving as a burden; 20 to 30 percent experience depression; and many become socially isolated. Caregiving of an elderly disabled individual, for example, can be a major source of distress and may lead to depression and increased health problems in the caregiver spouse. Data show that the need for informal caregiving may occur in all ages, races, and both genders. Data from national surveys are supported by individual studies that have identified caregiving problems, strains, and burdens of caregiving as well as the satisfactions of providing care.

The NINR is seeking ways to increase nursing research in this area, aiming to encourage research in understudied areas and to encourage those already engaged in caregiving research to add new levels of knowledge to the field. After reviewing what is known about informal caregiving, the workgroup identified new research opportunities to increase scientific knowledge and to support advances in clinical practice and to have an impact on the health care system's awareness of the needs of caregivers and caregiving. The recommendations are summarized below.

Workgroup Discussion

Discussion during the two-day meeting was extensive and productive. Participants focused their discussion around a previously identified framework of population groups and caregiving issues. The state of caregiving science was considered for several potential research areas of opportunity including chronic illness, aging, technology-dependence, cognitive impairment, understudied cultural and ethnic diversity groups, caregiver support systems, measurement of caregiving and its outcomes, and cost issues.

The group used different terms for informal caregiving including family care, caregiving, and non-kin caregiving. These terms are reflective of various research populations, however, in this report caregiver refers to all informal caregivers whether related to the care recipient or not and whether living in the same home as the care recipient or not.

A comprehensive list of research problem areas in informal caregiving was generated. This initial, lengthy list was analyzed for naturally occurring categories of research. All specific recommendations were then included or incorporated into the three major categories presented below. Priorities should not be inferred by the order of presentation of topics.

Research Opportunities

A. Informal Caregiving Populations

Most caregiving research has used convenience samples. As a consequence, population-based data regarding the prevalence of family care and variability in family care variables within the population is extremely limited. Research addressing this gap is needed. The major population groups are also not well represented in research studies. For example, research needs were identified for caregivers of all age groups, diverse minority and ethnic groups, and both genders. Caregiving also occurs in a wide range of care

recipient health conditions, including but not limited to, stroke, normal functional impairment of aging, physical disabilities, chronic diseases such as arthritis and diabetes, and developmental disabilities. Many of these care recipient health conditions, along with other conditions, are not well represented in the literature. Studies that focus on understudied populations, or that include larger subsets within studies of major populations, are needed for appropriate data analysis and the interpretation of commonalities and unique features of caregiving. It is not known whether caregiving varies, and if so, in what ways, across these understudied populations.

Informal caregiving groups that could benefit from more research include, but are not limited to, the following:

1. Population-based research to describe the prevalence of caregiving in the population, and describe the variability of caregiving experiences.
2. Children or grandparents as caregivers in families (intergenerational caregiving).
3. Caregivers with care recipients who are children or young adults (excluding parenting as caregiving).
4. Hard-to-reach groups and overwhelmed caregivers.
5. Ethnic minority populations, including, for example, how ethnicity interacts with the effectiveness of interventions.
6. Groups by care recipient illness/disability: The different needs of caregivers relative to the type and severity of illness the care recipient has, e.g., persons with cancer, cardiovascular disease, diabetes, stroke, hypertension, physical disability (trauma, genetic, debilitating conditions), arthritis, or neurological conditions.
7. Diverse populations in various settings (rural, urban, inner city, geographic) and socioeconomic status.

2. Caregiver Knowledge, Skills, Support

The workgroup participants agreed that more research is needed to understand better the breadth and depth of critical caregiving skills, how caregivers best acquire the skills; and how key knowledge and skills change over time with transitions in recipient health. More information is needed about generic caregiver knowledge and skills as well as that needed for sophisticated caregiving requirements. Some examples of responsibilities of caregivers include: symptom management, care procedures/activities, knowing who to call when for health care/social services assistance, ensuring health care visits to health providers, medication management, prevention of complications, preventive care, identifying improving or worsening of condition, health crises, troublesome behaviors, physical and emotional dependency, and determining the necessity to institutionalize. These and many other caregiving responsibilities are well documented. Research opportunities remain in further understanding of and interventions for improving knowledge, skills, and support needed by caregivers in order for them to carry out the responsibilities more effectively.

The topics in this and the next section below should be understood to include culturally competent methods and interventions as standard components of any study.

1. Detection and response to gaps in the quality of informal caregiving.
2. Generic knowledge, skills, and health care resources that are applicable to all or most informal caregivers for various care intensities and health conditions.
3. Skills and supports caregivers need at different points in the trajectory of the care recipients' health state, including physical, cognitive, and emotional changes.
4. Specific nature of the psychosocial and social support needs of caregivers. What formal or informal support interventions are most effective and efficacious for the caregiver?
5. Interventions to assist the caregiver to help the recipient achieve the desired health outcomes (example: coaching).
6. Interventions to improve caregiver knowledge and ability to problem solve, make care management decisions, understand the care recipient's health condition, and enhance the desired health outcomes of the care recipient, and to include recipient input to the process. A related topic is caregiver needs related to sorting through their options and then making decisions on behalf of their family member and themselves.
7. Understanding and utilizing information from communication-based technologies, including computers and health care equipment, to assist daily decision-making and care by caregivers. Education, safety, and human factors related to home care technologies, and long-term outcomes of caregiving involving technology for caregivers and families.
8. Interventions to improve ongoing caregiver use of formal and informal services available in communities.
9. Use of multidisciplinary teams to address measurement of intervening factors and critical outcomes. (Include both psychometricians and statisticians on multidisciplinary research teams for instrument development to maximize the use of emerging instrument development technologies.)

3. Impact on Caregiver

Impact on the caregiver is often equated to the burden, stress, or strain of caregiving although several studies show that many caregivers do not feel burdened by caregiving. Studies have shown that there is a continuum of experiences ranging from full satisfaction to dissatisfaction or extensive role strain with caregiving. A number of factors have been found as affecting the negative aspects of caregiving. For example, the circumstances of caregiving, including caregiver and care recipient characteristics, health and functional status, and severity of the care recipient's health condition play a role in the impact of caregiving on the caregiver. And many caregiver families must cope with the often significant financial cost of caregiving. Little is known about the long-term impact of caregiving on caregiver burden and health. At least one study found an increase in mortality in distressed caregiver spouses. Special categories of caregivers may face unique challenges. Caregiving for persons of any age with physical disabilities or mental illnesses are examples of special groups that may have unique burdens for the caregiver. Caregivers who work or who have other family responsibilities or who live in geographically isolated areas may have special difficulties in juggling all of their roles.

1. Understanding how successful caregivers maintain healthy partnerships with their care-recipients, other family members, and formal health care providers.
2. Interventions that improve caregiver ability to maintain their own health and a healthy lifestyle.

3. Influence of previous family dynamics on the outcomes of caregiving for caregivers and recipient (examples: effects of positive, supportive dynamics or negative dynamics such as abuse, neglect, aggression).
4. The outcomes of family caregiving and chronic illness relative to caregiver personal growth and satisfaction, and what happens to caregivers when the care recipient dies or is placed in a long-term care facility.
5. Ethical dilemmas faced by family caregivers and how these influence the outcomes of caregiving for recipients and caregivers.
6. The relationship between the caregiver and care recipient over time and the effects on both the dyad, other family members, and other social relationships (examples: the ebb and flow of the relationship through chronic illness patterns that may be accompanied by episodic and emergent health crises; the levels of formal and informal support necessary to sustain and supplement the caregiving relationship over time).
7. The extent of burden experienced by children, siblings, or other family members and the level of their participation in caregiving, including non-kin caregiver burden.
8. The impact on the caregiving relationship when the caregiver also has impaired health.
9. The physiological, mental health, and psychosocial effects on the caregiver; and interventions to improve or manage detrimental effects.
10. Other caregiver impact issues include depression; respite needs; family conflict; health care for caregiver; evaluation of caregiving effectiveness; social isolation; distressed caregiver; emotional fluctuations (anger, fear, depression, frustration, helplessness, ongoing stress); and caregiving compensation strategies.