

EXECUTIVE SUMMARY: PROFESSIONAL PARTNERS SUPPORTING FAMILY CAREGIVERS

Kathleen Kelly

Family Caregiver Alliance

Susan C. Reinhard

AARP Public Policy Institute

Ashley Brooks-Danso

Gero-Ed Center

TODAY, MORE THAN three-quarters of adults who live in the community and need long-term care depend on family and friends as their only source of assistance with activities of daily living (such as bathing, dressing, and eating) or instrumental activities of daily living (such as transportation and managing finances) (Thompson, 2004). Research suggests that the more than 33 million caregivers who provide help to someone age 50 or older (National Alliance for Caregiving & AARP, 2004) often assume these responsibilities for a relative, partner, or friend with little preparation for the role and little ongoing support. The results frequently are poor physical and mental health for the caregiver and preventable institutionalization for her or his loved one. A 2008 Institute of Medicine report, *Retooling for an Aging America: Building the Health Care Workforce*, emphasizes the need to prepare professionals, paraprofessionals, and informal family caregivers for an older U.S. population (Committee on the Future Health Care Workforce for Older Americans, 2008).

Social workers and nurses are at the forefront of interacting with and providing sup-

port to family caregivers. In order to prepare current and future professionals in these fields, the AARP Foundation, together with the *American Journal of Nursing*, the Council on Social Work Education, the Family Caregiver Alliance, and the Rutgers, the State University of New Jersey Center for State Health Policy, received funding from the John A. Hartford Foundation and the Jacob and Valeria Langeloth Foundation for an interdisciplinary project on family caregiving for older adults. This project aims to bring together experts to advance family caregiving by identifying additional and further developing existing best practices in nursing and social work to help families care for older adults. The project will begin to lay the groundwork for producing a cadre of nurses and social workers who embrace a patient- and family-centered care perspective. The professionals will partner with families in new ways to:

- improve families' ability to better manage their everyday care responsibilities, reduce their own burdens and health risks,

and promote a better quality of life for both the older adults receiving care and the family members providing it

- improve professionals' ability to assess the needs of family, friend, and neighbor caregivers; provide caregivers with the information and skills needed to deliver care; and lead in the development of family-friendly policies, practices, and environments across health care settings.

The Invitational Symposium

As a first step in this project, family caregiving experts from nursing and social work participated in a two-day interdisciplinary invitational symposium, *State of the Science: Professional Partners Supporting Family Caregivers*. At this symposium, held in Washington, DC, January 29 and 30, attendees began to identify and discuss ways to address how nurses and social workers can better support caregivers. The objectives of the symposium were to

- describe what is known about the demographics and characteristics of family caregivers in the United States and the issues and obstacles that influence their ability to care successfully for family members
- identify the competencies and knowledge that family caregivers need
- describe the competencies that nurses and social workers need to best support family caregivers
- identify best practices for supporting family caregivers
- identify the gaps in the science and the barriers to implementing interventions for supporting caregiving across service settings
- identify clinical, educational, research, and policy priorities for developing best practices for promoting and supporting family caregiving.

The planning group for the symposium invited 56 experts from nursing and social work practice, education, research, and policy settings as well as representatives from other groups and organizations involved in caregiving, including consumer advocacy, regulatory, and health care. Nurses, social workers, and other experts in caregiving were asked to write papers reviewing the current state of the science in designated areas. The papers underwent peer review, were sent to all symposium participants prior to the event, and later were modified according to feedback from participants. Highlights of these papers were presented at the symposium with the aim of delineating the evidence currently available to guide nurses and social workers in better supporting the family caregivers of older adults. Special focus was placed on cultural diversity, disparities in access to care, sex, and other variables that affect the success of family caregiving. The papers were subsequently edited for publication in this supplement to *AJN*.

During the symposium, participants worked in small groups to identify clinical, educational, research, and policy priorities and strategies for developing best practices to promote and support family caregivers. Specific tasks for the small groups included

- identifying the knowledge and competencies nurses and social workers need to support family caregivers (see Table 1).

TABLE 1. Knowledge and Competencies Nurses and Social Workers Need to Support Family Caregivers

Knowledge
<ul style="list-style-type: none"> • Be knowledgeable about the complexity of relationships among caregiver, care recipient, and family members • Understand the challenges (physical, emotional, financial) and rewards (relationship fulfillment, personal satisfaction) of caregiving in general and of specific diagnoses and courses of illness (such as Alzheimer’s disease, stroke, and cancer) • Acknowledge caregivers as being a central part of health care systems • Be aware of the contexts in which family caregivers operate, including the policies, eligibility requirements, and financial concerns that affect them • Be familiar with the resources available to family caregivers, including support services and technologies • Recognize the indicators of caregiver burden (such as depression, anxiety, deteriorating health, financial insecurity, and social isolation) • Be knowledgeable about the financial challenges of caregiving and the resources and tools that may help family caregivers address these challenges (such as paid and unpaid leave; supports that enable caregivers to continue working, such as adult day care, respite care, and employer best practices in supporting caregivers; and retirement savings mechanisms) • Appreciate the differences that exist among caregivers and families in cultural beliefs, ethnicity, race, religion, sex, and sexual orientation
Competencies
<p>Communication</p> <ul style="list-style-type: none"> • Engage in active listening and express empathy and respect for each caregiver • Translate information across many systems and providers • Transfer information from family caregivers to providers and vice versa • Use sound interviewing, mediation, and engagement skills • Employ good teaching and coaching skills • Respond to the legal and ethical issues that can arise in family caregiving situations, including abuse <p>Assessment and practice</p> <ul style="list-style-type: none"> • Identify, understand, and articulate each caregiver’s circumstances, needs, strengths, and goals • Understand the caregiver’s cognitive abilities and cultural and spiritual situation (including the ability to perform direct care)

Continued

- recommending ways to develop nurse and social worker competencies to support family caregivers (see Table 2).
- recommending strategies for promoting a new model of care that includes both the family caregiver and the care recipient and that will permit caregivers to be reimbursed for the services they provide (see Table 3).
- recommending other strategies that will enhance the ability of nurses and social workers to support caregivers, including ways to change the culture of organizations, set quality measures that include

TABLE 1. (continued)

-
- Anticipate the needs of the caregiver and the caregiver’s family
 - Develop, implement, evaluate, and modify care plans in collaboration with family caregivers
 - Assist family caregivers in identifying and accessing services

Collaboration

- Develop and participate in an interdisciplinary team approach to provide support to family caregivers
- Work with multiple health care and social service systems
- Seek out, create, and maintain new partnerships
- Establish and maintain collaborative relationships with families

Leadership

- Be knowledgeable about best practices in changing organizational cultures to embrace interdisciplinary approaches that include paraprofessionals, patients, and family caregivers
- Lead an interdisciplinary team in providing care
- Advocate on behalf of family caregivers
- Be creative and flexible in developing and implementing solutions to caregivers’ challenges
- Identify and implement evidence-based practices

Measure and disseminate outcomes

Note: In this table, “family caregiver” is defined as the dyad of patient and primary informal caregiver(s); it includes a focus on the patient. The competencies presented here can be integrated into other nurse and social worker practice competencies already included in a curriculum.

TABLE 2. Recommendations for Developing Nurse and Social Worker Competencies to Support Family Caregiving

-
- Include content on family caregiving in the core curriculum
 - Evaluate competency by using standardized techniques, such as an Objective Structured Clinical Examination or videotaped reviews
 - Develop formally recognized preceptorships with professional mentoring and “train the trainer” programs, especially for postgraduate and continuing education
 - Institute interdisciplinary training for nurses and social workers

Continued

TABLE 2. (continued)

-
- Have nurses and social workers shadow each other to better understand the other's role
 - Employ role-playing and use videotaping and other learner-centered strategies in the curriculum
 - Develop multimedia and Web-based teaching strategies
 - Secure funding for a demonstration project that would teach nurses and social workers together
 - Provide experiential learning by assigning students to spend a day with a caregiver
 - Bring caregivers and home health aides into the classroom as presenters and mentors
 - Adapt the hospice approach as a model for family caregiving
 - Define and disseminate best practices for the support of family caregivers
 - Influence accreditation bodies to incorporate education into practice, including assessment, problem solving, and experiential learning
 - Encourage funders to pay for educating family caregivers
-

TABLE 3. Primary Recommendation: Develop and Promote a Patient- and Family-Centered Service Paradigm

Provide access to care

- Follow the family over time and respond to its needs with flexible, evidence-based interventions at the right time and in the right dosage across settings
- Enable any caregiver or family member to access services and support as needed
- Create a patient-family advocate or care manager navigator
- Develop and integrate an electronic record for family care
- Remove real and perceived barriers to family access to health information, such as the Health Insurance Portability and Accountability Act

Create or change policy

- Change reimbursement systems to allow flexible support for services
- Allow reimbursement for caregiver assessment
- Bundle payments, including transitional care
- Create a flexible funding model so family caregivers can purchase the support services of their choice
- Formalize the rights of caregivers to be part of care planning
- Make the case for supporting family and informal caregivers at the Senate committee hearing on family caregiving
- Call for an Institute of Medicine report on family caregiving
- Expand and fully fund Title III-E of the Older Americans Act, the Administration on Aging's National Family Caregiver Support Program, to include quality standards for competent staffing, technologic assistance, outcomes, intervention protocols, and assessment
- Fund centers of excellence for family-focused care, including a clearinghouse of materials

Continued

family caregivers in the care delivery system, integrate technology, and enhance the public's awareness of and the education of professional and nonprofessional caregivers (see Table 4).

- creating an agenda for future research on family caregiving (see Table 5).

The symposium participants concluded that, given the increasing number of older adults, it will

TABLE 3. (continued)

Fund research

- Develop research to lend scientific and analytic support for outcomes related to both patients and family caregivers, factors related to preventing emergency room visits and hospital admissions, and the best "dose" of nurse and social worker interventions with family caregivers
- Recommend that the Medicare Payment Advisory Committee (MedPAC) undertake an analysis, under interdisciplinary leadership, of a model focusing on the family unit and documenting how transitions in care occur
- Compare best practices and evidence-based practitioner competence for improving caregiver outcomes
- Study naturally occurring caregiver systems
- Study information systems that facilitate sharing across settings
- Develop and evaluate funding models, including demonstration projects that show cost savings, and make the business case for family caregiving services

Increase awareness

- Coordinate advocacy on the federal level, to be convened and championed by an impartial entity that brings together stakeholders (such as professional and caregiver organizations, universities, funders)
 - Create a public awareness campaign on family caregiving that is modeled on Johnson & Johnson's Campaign for Nursing's Future
 - Disseminate a "caregiver bill of rights" that emphasizes the importance of having an advocate and the right to information on resources
 - Develop a marketing campaign backed by a coalition of nurses, social workers, and physicians to educate policymakers and create grassroots support for advocacy and social policy changes that support family caregiving
 - Identify leadership, excellence, and champions in organizations and among employers who support family caregiving
 - Send the message to employers that they can improve morale and increase retention by considering the needs of employees who are family caregivers and by taking a proactive rather than a crisis-management approach
-

TABLE 4. Recommendations for Strategies to Increase the Ability of Nurses and Social Workers to Support Family Caregivers

Change the organizational mindset of health care providers through an interdisciplinary approach to education

- Use best practices in changing organizational cultures to embrace interdisciplinary team approaches that include paraprofessionals, patients, and family caregivers
- Identify opportunities to point out to health care organizations the cost-effectiveness of supporting family caregiving
- Engage the Institute for Healthcare Improvement as a partner in identifying innovative practices and policies
- Identify case examples that have outcome data, benchmarks for accrediting bodies, and strategies to address concerns of trustees and chief executives of organizations

Develop quality measures related to family caregiving (quality of care and quality of life) and integrate them into national performance measures and the reimbursement system

- Review all performance measurement sets and use existing criteria for assessment, ensuring that the measures for care processes and outcomes evaluate the support, adequacy of education, and care of the family caregiver as well as the willingness and capacity of family members to be caregivers
- Include measures that survey family caregivers on their needs, concerns, and satisfaction with care
- Establish a steering committee of nursing and social work experts, researchers, and consumer organizations to recommend measures and identify a research agenda
- Ensure that nurses and social workers with expertise in family caregiving are represented in national performance measurement groups such as the Quality Alliance Steering Committee, the National Quality Forum, the Joint Commission, and the MedPAC

Integrate technology into the care delivery system to support, enhance, and extend the ability of nurses and social workers to help both patients and family caregivers

- Analyze the available technology to identify its feasibility for use by nurses and social workers as well as its potential for improving caregivers' outcomes
- Learn from and work with the disability community on technology issues to take advantage of their experience
- Identify funding sources to support technology, including industry, the Small Business Administration's Small Business Innovation Research Program, the Department of Veterans Affairs, insurance companies, the Centers for Medicare and Medicaid Services, and the National Institute for Standards and Technology
- Disseminate information on technology and available resources to both professionals and families

Continued

TABLE 4. (continued)

Require caregiving-related content in professional education

- Implement a caregiving curriculum for nurses and social workers that honors the interdisciplinary nature of practice
- Evaluate the level of competence of social work and nursing students in supporting family caregivers by using standardized simulations and other objective performance assessment measures
- Mandate certification or licensure requirements in key elements of family care, such as assessment and care coordination
- Create a model for interdisciplinary home visits
- Develop national competency standards for care managers that include a family caregiving focus

Develop education programs for caregivers

- Use popular Web sites and online assessments to provide information and education
- Develop protocols and criteria to match the educational needs of caregivers with specific strategies
- Include caregivers in nurse and social worker training programs on family caregiving
- Make the existing programs more widely available to nurses and social workers to enhance their awareness of these resources

Promote a public awareness campaign on family caregiving issues (see “Increase Awareness” in Table 3)

TABLE 5. Proposed Agenda for Research on Family Caregiving

Design and Testing of Evidence-Based Interventions

Theory

- What are the theoretical underpinnings of professional interventions for assisting family caregivers?

Models of care

- Which transitional-care models and provider team composition (such as a nurse-and-social-worker team versus one provider working alone) provide the best caregiver and care recipient outcomes?
- What evidence-based interventions promote good outcomes when using a collaborative (nursing and social work) model of care?
- How do care recipient and caregiver outcomes differ for new and blended models of care?

Interventions

- What are the best practices for promoting good outcomes for care recipients and caregivers?

Continued

TABLE 5. (continued)

-
- What are the best methods for identifying at-risk caregivers who should be targeted for intervention?
 - What are the most effective interventions for promoting family caregiver knowledge and skill, including the best timing of the intervention along the caregiving trajectory, the best dose or intensity of the intervention, and the best health team composition?
 - How do risk factors such as advancing age and comorbidities affect the selection and effectiveness of an intervention?
 - Do age, comorbidities, and complexity of care affect patient and caregiver outcomes with single and multidimensional interventions for family caregiving?
 - How do factors such as the family's socioeconomic status, culture, geographic location, education, structure, and religion influence the effectiveness of interventions?

Outcomes

- What measures already exist that are specific to caregiver outcomes, have the most sensitive scales, are reliable and valid, and are useful in evaluating the effectiveness of interventions in clinical settings?
 - What measures need to be developed to measure caregiver outcomes?
 - What effects do nursing and social work interventions have on the quality of care, care coordination, and cost of care?
-

Translation of Evidence-Based Interventions into Practice

- Which family caregiver interventions are best practices or priorities ready to be translated into practice?
- What knowledge and skills do caregivers believe they need?
- What are the best ways to incorporate best practices into systems of care?
- What benefits do nurse–social worker collaborative interventions have for outcomes for family caregivers and care recipients (compared with those with a noncollaborative or single-profession model)?
- Which practice setting provides the best location for family caregiver interventions?
- What is the best way to reach low-income family caregivers?
- How can translational science be used to better disseminate and utilize research for family caregivers?
- What factors are most important in institutional and community-based health care organizations for translating and sustaining nursing–social work interventions with family caregivers?
- How does nurse–social worker collaboration enhance family caregivers' use of community services?
- What factors promote the usability of community services for family caregivers?

Continued

take strategic collaboration among members of the nursing and social work professions to lead the way in ensuring the good health and well-being of the growing number of caregivers of older adults.

References

Committee on the Future Health Care Workforce for Older Americans; Institute of

TABLE 5. (continued)

Cost-Effectiveness of Caregiver Interventions
<ul style="list-style-type: none"> • What is the economic impact of interventions targeted to both care recipients and caregivers? • Does family caregivers' use of community services improve their quality of life as well as care recipients' clinical and financial outcomes? • What economic benefit does the whole family receive with increased use of community services? • What are the cost advantages to businesses and corporations of instituting caregiver support programs that broadly define "family"? • What incentives might encourage businesses to provide on-site services to caregivers and care recipients? • What economic models can be used for payment of services as part of employee health benefits? • What recommendations for payment of specific caregiver interventions might be given to payers, providers, and purchasers of services?
Technology
<ul style="list-style-type: none"> • What technology that promotes family care will allow employed caregivers to be more productive (fewer days lost from work, fewer interruptions)? • How might technology be used to improve quality of life in different community-based settings, such as adult day care and other programs where caregivers can monitor the care recipient from the work setting? • How does the enhanced use of durable medical equipment result in improved family caregiver and patient outcomes? • What are the benefits of technologic interventions compared with nontechnologic interventions for caregiver outcomes and clinical patient outcomes? What is the cost of that care? • What effects do technologic interventions (such as the effect on human interaction and patient centeredness) have on care recipients and caregivers? • What technologic devices, such as a DVD, would caregivers chose to support them in caregiving?

- Medicine. (2008). *Retooling for an aging America: Building the health care workforce*. Washington, DC: National Academies Press.
- National Alliance for Caregiving & AARP. (2004). *Caregiving in the U.S.* Bethesda, MD: National Alliance for Caregiving; Retrieved April 2004 from <http://www.caregiving.org/data/04finalreport.pdf>
- Thompson, L. (2004). *Long-term care: Support for family caregivers*. Washington, DC: Long-Term Care Financing Project, Georgetown University. Retrieved March 2004 from <http://ltc.georgetown.edu/pdfs/caregivers.pdf>

Kathleen Kelly is the executive director of the Family Caregiver Alliance in San Francisco. **Susan C. Reinhard** is the senior vice president for Public Policy at AARP in Washington, DC, and chief strategist for the Center to Champion Nursing in America. **Ashley Brooks-Danso** is codirector of the Gero-Ed Center (National Center for Gerontological Social Work Education) housed at the Council on Social Work Education in Alexandria, VA.

Reprinted with permission from the *American Journal of Nursing*. This article was first published as a supplement to the September 2008 issue of the *American Journal of Nursing*. Continuing education contact hours are available to nurses at www.NursingCenter.com/ajnfamilycaregivers.

Contact author: Kathleen Kelly, kkelly@caregiver.com. Kelly, Reinhard, and Brooks-Danso are the coeditors of this supplement. The authors of this article have disclosed no other significant ties, financial or otherwise, to any company that might have an interest in the publication of this educational activity.