

DISCUSSION AND RECOMMENDATIONS: NURSES AND SOCIAL WORKERS SUPPORTING FAMILY CAREGIVERS

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FAMILY MEMBERS—whether people related by birth and marriage or friends and neighbors (sometimes called a “family of choice”)—are the main caregivers for millions of older Americans. These family caregivers assist those they care for with activities of daily living such as bathing and dressing, with instrumental activities of daily living such as transportation and management of finances, and with health care such as medication administration. Usually, family caregivers assume these responsibilities with little preparation. Nurses and social workers can do much to educate family caregivers about their roles and to support them as chronic care providers.

Fifty-five nurses, social workers, advocates, and other leaders in family caregiving met on January 29 and 30, 2008, in Washington, DC, for an invitational symposium. The collaborative consensus symposium was a joint project of the AARP Foundation, the *American Journal of Nursing*, the Council on Social Work Education, and the Family Caregiver Alliance. The John A. Hartford Foundation and the Jacob and Valeria Langeloth Foundation generously provided funding for this project.

Attendees explored the state of the science concerning nurses’ and social workers’ interventions with family caregivers. Participants heard and responded to presentations from the authors of the articles in this publication. In addition, brainstorming sessions with small groups of about seven symposium participants each brought diverse backgrounds and perspectives to the table. At the end of each small-group work session, each group presented its conclusions to the group as a whole. Topics included the following:

- What needs and concerns do family caregivers have? How does caregiving affect the physical and mental health of the caregiver?
- What competencies do nurses and social workers need to support family caregivers? What strategies can help nurses and social workers develop these competencies?
- What models of care and best practices for nurses and social workers help them support and educate family caregivers?
- What factors enable nurses and social workers to provide the support that family

caregivers need? Which of these factors are the most important? What strategies can address these top priorities?

- What are the priorities for research on nurse and social worker support of family caregivers?

This article and the tables in the Executive Summary (see page 00) present the work of the groups at the symposium. All participants received drafts of this material and had the opportunity to make comments and suggest revisions.

Throughout the symposium, participants repeatedly mentioned certain themes. They emphasized the need for:

- a new health care delivery model that recognizes the care recipient and the caregiver—the family—as the unit of care
- coordination and continuity of care
- an interdisciplinary team that includes the nurse and social worker as well as the family caregiver
- better understanding by team members of their colleagues' roles and how to work collaboratively to integrate the caregiver into the team
- using cost-effective technology, including the telephone, interactive video, the Internet, and monitoring devices, as tools for education and support
- making the business case for providing support to family caregivers by gathering and disseminating evidence of the economic value of family caregiving
- reimbursing nurses and social workers for the time they spend with families
- research to determine the best practices for supporting caregivers

Nurse and Social Worker Competencies

The first issue that was addressed was what knowledge and competencies nurses and social workers need to have to support family caregivers (see Table 1 in the Executive Summary, page 7). Participants then considered what strategies will help develop these competencies (see Table 2, page 8).

Knowledge

The nurse or social worker must understand how complex caregiving is, especially for a caregiver who has no background in providing physical care for an ill or frail elderly person and whose familial relationship with the care recipient may create significant stress. Understanding how to use technology that can help family caregivers, being familiar with community and other resources, and knowing what financial options are available for both short- and long-term needs are also essential.

Communication Skills

The nurse or social worker must be able to communicate information to the family caregiver in a nonjudgmental, supportive manner. This requires knowledge of family systems and dynamics, excellent communication skills, and the ability to translate science into practice.

Assessment and Practice Skills

The new model of care delivery sees the family unit as the client. The nurse or social worker must be able to respond to the needs of the family using culturally appropriate interven-

tions. This begins with a multidimensional assessment of the strengths and needs of the caregiver as well as the care recipient. Then the nurse or social worker must develop a care plan that is tailored to that particular situation. Being able to teach and coach caregivers on skills is essential because the caregiving process changes over time. The social worker or nurse must be able to anticipate the family's needs and offer guidance, as well as help the caregiver develop appropriate problem-solving skills so she or he can respond to unanticipated needs that arise.

Collaborative and Leadership Skills

Nurses and social workers must be able to identify the resources that are available from multiple sources and match them to the family's needs. They need to be able to work across disciplines and to embrace the caregiver as part of the interdisciplinary team. Because the current health care system is imperfect, nurses and social workers must advocate for change.

Competency-Building Strategies

Most of the strategies that were suggested for developing these competencies were educational, starting with implementing nursing and social work curricula that focus on supporting family caregivers. Professional mentors and preceptors could assist postgraduates. A variety of educational methods, including role-playing, multimedia approaches, and Web-based teaching strategies, could be used to prepare less experienced nurses and social workers for situations that might occur.

The competency-building strategies that were suggested emphasized taking an interdisciplinary approach, such as jointly training

nurses and social workers and providing opportunities for them to shadow each other. Experiential learning, with family caregivers and others who work in the home setting (such as home health aides) serving as mentors and guides, would help, as would adapting the hospice approach, which successfully integrates family caregivers into a multidisciplinary team.

Other strategies suggested were disseminating information on best practices and establishing benchmarks and standards for services. Certification of nurses and social workers as specialists in family caregiving could be tied to successful demonstration of competencies.

Strategies to Promote Support of Family Caregivers

On the second day of the symposium, attendees explored the factors that influence nurses' and social workers' ability to support family caregivers. After narrowing the list to the factors they considered to be the most important, each group identified strategies for addressing two of them. The extensive discussion that followed is summarized here and in Tables 3 and 4 of the Executive Summary.

New Model

Focusing on the family unit was without question the factor most frequently noted by participants to be essential to supporting family caregivers. Many strategies for enhancing this new health care delivery model were suggested (see Table 3 on page 9 of the Executive Summary).

Because the goal is to follow the family over time and respond with flexible, evidence-based interventions at the right time and in

the right dosage across all care settings, all caregivers and family members must be able to access services and support as needed. A family advocate or navigator can enhance the access and care provided by this model. Developing an integrated electronic record for family care was also suggested.

The new model of family care will require changes in how nurses and social workers are reimbursed to permit them to provide flexible support. For example, nurses and social workers will need to be reimbursed for assessing caregivers. Possibilities include bundled and capitated payments for the family.

Policymakers have to become involved for reimbursement changes to occur. One group of attendees called for a congressional hearing on family caregiving, and another group suggested radically expanding Title III-E of the Older Americans Act, which grants informal caregivers and their charges rights to assistance, information, and supplemental services. Several people called for the Institute of Medicine to produce a report on family caregiving. The hoped-for result, according to symposium participants, is the development of a business case for family caregiving services, one that would be bolstered by demonstration projects that show that the new delivery model saves money and economic analyses that quantify how much workers who are family caregivers lose in wages and productivity.

Despite the wide prevalence of family caregiving, it may be a new concept to many people who have had no direct experience with it. To raise public awareness about family caregiving, participants suggested implementing both a marketing campaign backed

by a coalition of nurses, social workers, and other professionals and a coordinated advocacy program that brings together stakeholders such as professional organizations, caregiver organizations, and funders.

Organizational Mindset

To best support family caregivers, the organizational mindset and culture need to change. One strategy for achieving meaningful change is to learn about flaws in the system from the paid home care workforce, such as paraprofessionals and aides. Demonstration projects and case studies with outcomes data would help to convince trustees and chief executives that a new organizational mindset regarding family caregiving is needed. Symposium participants again emphasized the importance of building a business case for supporting family caregivers, in part by identifying ways that family caregiving saves the government and private health care organizations money.

Quality Measurement

Integrating family caregiving quality measures—those concerning both quality of care and quality of life—into national performance measurements would improve nurses' and social workers' support of family caregivers. Criteria from existing performance measurement sets could be used or adapted for this purpose. Experts from the nursing and social work fields should be represented in national performance measurement groups such as the Quality Alliance Steering Committee, the National Quality Forum, the Joint Commission, and the Medicare Payment Advisory Committee. An independent steering committee of nurse and

social worker experts, researchers, and consumer organizations could also establish quality measurements for family caregiving.

Technology

Technology that can be integrated into the care delivery system could support and expand the ability of nurses and social workers to help both patients and family caregivers. Symposium participants noted that the disability community might be able to provide information of value to family caregivers on technology issues. The feasibility and acceptability of the technology available for use by nurses and social workers, as well as its effectiveness in improving the outcomes of caregivers, need scrutiny. Once this analysis is completed, information on what technology is useful and what resources are available should be given to both professionals and families.

Funding sources for any technology deemed useful need to be identified. Possible sources include insurance companies, the Centers for Medicare and Medicaid Services, the Department of Veterans Affairs, and the Small Business Administration's Small Business Innovation Research Program.

Education

Education of professionals, caregivers, the business community, and the public in general will enhance support of family caregivers. Echoing some of the themes discussed regarding competencies, symposium attendees called for creating interdisciplinary caregiving curricula for nurses and social workers and including caregivers in the training. Interdis-

ciplinary home visits could be included in professional education. Certification or licensure in key elements of family care, such as assessment and care coordination, would ensure that nurses and social workers have an appropriate foundation of knowledge. In addition, national competency standards for care managers should include family caregiving.

Caregiver learning will improve when protocols or criteria to match their educational needs with specific educational strategies are developed. The Internet can also be useful in caregiver education; for example, professionals could use online assessment tools to educate caregivers and identify their needs. Web sites could also enable caregiver self-assessment, education, and peer support.

Symposium participants called repeatedly for public awareness campaigns about family caregiving. One target of such campaigns should be employers, who need to be aware that they can improve morale and improve retention by considering the needs of employees who are family caregivers. Identifying leaders and champions and developing a network of these champions both within and outside an organization, including employers, would extend the reach and improve the effectiveness of public awareness campaigns.

Research Priorities

The symposium's final small-group work session focused on identifying research priorities. Each group selected what it considered to be the top three research questions and presented its findings to all participants. After the symposium, two attendees (Karen Robinson, DNS, RN-BC, FAAN, social policy fellow,

American Academy of Nursing/AARP and professor, University of Louisville School of Nursing; and Barbara Given, PhD, RN, FAAN, associate dean of research at Michigan State University College of Nursing) organized these questions into a research agenda, which was given to all symposium participants for comments and revision. The consensus research agenda appears in Table 5 of the Executive Summary (see page 12).

Design and Testing of Evidence-Based Interventions

Because the emphasis throughout the symposium was on a new model of care delivery that focuses equally on the family caregiver and the care recipient, many of the research topics suggested concerned developing the best interventions for both parties. One goal is to determine what independent variables promote good outcomes in the collaborative nurse–social worker model of care. As part of this research, new outcome measures at the family level—including the new model’s impact on the quality of life of the caregiver and the care recipient, their satisfaction with services, and their utilization of resources—need to be developed.

The underlying intervention research question asks, Under what circumstances, for what population, and at what dose is a specific intervention effective? Given the unique nature of family caregiving situations, research should help determine the interventions that work best for families who are dealing with complex comorbidities and for people of different cultures. Many caregivers are themselves vulnerable or isolated, such as elderly people who care for their spouses and dis-

abled adults who care for their parents. Tools are needed to help identify which caregivers are most in need of professional intervention.

Ideally, all interventions would be tested in randomized controlled trials. However, because this takes time and resources, interventions will have to be prioritized for testing.

Translation of Evidence Into Practice

Once research has provided evidence of an intervention’s value, the challenge becomes translating the research into practice. One aspect of this challenge is determining the best way to reach people of diverse socioeconomic and cultural groups in a variety of practice settings. To do this, professionals may need to understand how caregivers perceive their own needs for increased skills and knowledge. Translating research into practice also involves effectively disseminating information to professionals and to health care organizations, whose support is critical to sustaining nurses’ and social workers’ work with family caregivers.

Cost-Effectiveness

Making a business case for nurse and social worker support of family caregivers means that the economic impact of these professionals’ interventions must be determined. What benefits does the family realize as a result of increased caregiver support? What impact do caregiver interventions have on the care recipient? Similarly, what impact do programs for the care recipient have on the caregiver?

Economic issues need to be examined from the payers’ perspective as well. What specific caregiver interventions should insurers cover? Can employers be encouraged to provide serv-

ices, accommodate flexible schedules, permit telecommuting, and grant paid leave to family caregivers as part of a benefit package?

Technology

Symposium participants were excited about the potential technology has to enhance caregiving, and they had suggestions for research and practice. Well-designed studies should look at the impact of technologic interventions on caregivers and care recipients. The questions to be examined include: How can technology improve the quality of life in different

settings? Which technologies are most beneficial to the caregiver? Can use of technology allow employed caregivers to be more productive, for example by enabling them to check on the care recipient remotely from the worksite? How can technology be best matched to the needs and abilities of caregivers? Does the use of technology change the interaction between the caregiver and care recipient or between the caregiver and health care team? Performing cost-benefit analyses of technologic innovations is vital to make the case for funding these enhancements to caregiving.

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