Family caregivers are indispensable, yet they often feel underappreciated and inadequately supported by nurses and social workers. When they visit a hospitalized loved one, they may never be asked, “How are you doing? How are you managing?” They need more help on two fronts: becoming better caregivers and avoiding becoming patients themselves.

With the coming dramatic increase in America’s older population over the next 40 years, families will continue to provide the principal support for vulnerable older adults. Accordingly, an increasing number of caregivers—including those over age 65—may be caring for elderly family members in more than one generation, risking consequences that include overburdening and poor health. With public policies shifting the focus of care from institutional to community settings, family caregivers are more often expected to provide care that has traditionally been given by nurses and social workers, ranging from emotional support and dressing changes to pain management. In its report Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving, the AARP estimated the economic value of family caregiving in 2006 at a stunning $350 billion, exceeding the total amount spent in 2005 by either Medicare ($342 billion) or Medicaid ($300 billion). Although caregiving certainly can be rewarding for all involved, it also has substantial costs. It can be highly stressful work, putting caregivers at risk for depression and anxiety, as well as causing financial problems. Helping caregivers to maintain their own well-being is essential for care recipients, as well. Caregivers’ well-being has been shown to affect care recipients’ rates of functional decline, institutionalization, and death.

As the preeminent professions serving older adults and their families, social work and nursing should collaborate to address the needs of family caregivers by

- calling for a shift from a biomedical model of care to one that’s truly patient and family centered. The unit of service must be the family, and family caregivers must be recognized as partners in care. Their concerns can’t be ignored if they’re to assume such a significant part of the care given to our aging population.
- ensuring better preparation for nurses and social workers so that both are competent in assessing family caregivers and intervening to help them.
- designing interventions and evidence-based guidelines for helping family caregivers.
- advocating public policies that will fund the assessment, care coordination, education, and testing of interventions to support the well-being of families providing long-term care to elders.

To move these aims forward, an invitational symposium, State of the Science: Professional Partners Supporting Family Caregivers, was held in Washington, DC, in January. This groundbreaking symposium was an AARP-led partnership with the Family Caregiver Alliance; the Council on Social Work Education; the Rutgers Center for State Health Policy; and the American Journal of Nursing, funded in part by grants from the John A. Hartford and the Jacob and Valeria Langeloth Foundations. This was the first national effort to bring together nurses, social workers, family caregiver advocates, and other experts in family caregiving to delineate the current evidence that guides nurses and social workers in supporting family caregivers of older adults. This interdisciplinary group also focused on cultural diversity, disparities in access to care, sex differences, and other variables that affect family caregiving.

This report, arising from the information presented at that symposium, emphasizes
- discussing what is known about the demographic characteristics and concerns of family caregivers in the United States and the obstacles they face.
- identifying the competencies and knowledge nurses and social workers need to best support family caregivers.
• describing the best practices for supporting family caregivers.
• delineating the priorities for future research on family caregiving.
• identifying strategies for enabling nurses and social workers to better support family caregivers in all settings.

The symposium was the beginning, not the end, of a historic collaboration between nurses and social workers on caregiving. Together with family caregiving advocates, members of both professions must elevate the concerns of family caregivers. Nurses and social workers can draw upon their distinct and distinctive strengths to shape research, education, and practice in ways that will better support family caregivers.

Many nurses and social workers may argue that workloads and reimbursement policies don’t allow them the time or administrative support to address the needs of family caregivers. But in fact, simply expecting everyone on the health care team to include the family in the plan of care and ask, “How are you doing?” is a start. We encourage you to read this supplement, use it in your own practice, and think of creative, collaborative ways to promote the health and well-being of family caregivers. This full report, which provides many other ideas for leading the paradigm shift to family-centered care, is available online at www.nursingcenter.com/ajnfamilycaregiving and www.gero-edcenter.org.

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On the Cover

W ang Wah Po, 104 years old when this photo was taken, emigrated from China to the United States when he was in his late 80s and became a citizen in 1997, at the age of 103. A volunteer from the On Lok senior housing facility where Po lives is pushing Po’s wheelchair across a San Francisco street so he can attend a men’s luncheon at a local restaurant.

“This image shows caregiving and volunteerism among our elderly,” explains New Jersey–based photojournalist Ed Kashi, who used a Leica M6 camera for this shot. “Here is a man in his 80s who came once a week to take Wang Wah Po to lunch. What an incredibly beautiful act.” Po passed away in 2000.

The photograph is one of many in Kashi’s book Aging in America: The Years Ahead, along with essays and interviews by his wife, filmmaker Julie Winokur. American Photo magazine named it one of 2003’s best photo books.

Today, some 20 million Americans are raising children while also caring for aging parents. Kashi and Winokur depicted their own experience as dual caregivers in the short film Sandwich Generation, which documents their move across the country with two children and a business to care for Winokur’s 83-year-old father, Herbie, who had dementia.

Kashi has authored four books, including Curse of the Black Gold: 50 Years of Oil in the Niger Delta, published this year, and Three, coming out in 2009. A native of New York City, he has taught photography in many countries and captured award-winning images in locales spanning the globe for National Geographic, the New York Times Magazine, Time, and Newsweek.

For more information about or to order a DVD of Sandwich Generation, go to http://mediastorm.org/0009.htm. For more on Kashi, see www.edkashi.com.

—Alison Bulman, senior editorial coordinator

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