

ACP: Family Caregivers Deserve Doctors' Support

BY DENISE NAPOLI

The 37 million “family caregivers” who care for chronically ill patients in the United States have become “an integral part of the health care system” and deserve recognition from physicians for that role.

That’s from a position paper issued by the American College of Physicians and endorsed by 10 professional medical societies, including the Society of General Internal Medicine, the American Academy of Hospice and Palliative Medicine, the American College of Osteopathic Internists, and the American Geriatrics Society.

Family caregivers—defined broadly as relatives, partners, friends, and neighbors—provide care for 90% of dependent community-dwelling patients with acute and chronic physical illnesses, cognitive impairment, and/or mental health conditions, according to the authors (J. Gen. Intern. Med. 2010 Jan. 12 [Epub doi:10.1007/s11606-009-1206-3]).

“Coping with physical, emotional, spiritual and financial challenges affects caregiver health and quality of life as well as patients’ health and quality of life,” they wrote.

Dr. Virginia Hood, chair of the ACP’s Ethics, Professionalism, and Human Rights Committee and coauthor of the paper, agreed. “Family caregivers are often the one constant the patient can count on to help coordinate care, navigate systems, communicate with multiple health care professionals, [and] be the repository of accurate health care information ... especially for people with chronic diseases,” she said in an interview.

“As physicians we need to understand and ensure that ethical principles of medical practice are relevant to and reflect the roles of all team members, including family caregivers, as well as teams themselves, as we try to improve care for our patients,” Dr. Hood added.

According to the report, “physician accessibility and excellent communication are fundamental to supporting the patient and family caregiver”—a potentially difficult mandate, given the current climate of rushed office visits and time constrictions.

For example, the authors cite a 2001 survey conducted by the Alzheimer’s Association that showed that although most family caregivers want information regarding what they can expect as the disease progresses, just 38% reported that the physician provided it (www.alz.org/national/documents/alzheimer-report.pdf).

“Physicians’ use of medical jargon and technical terminology can be confusing to family members,” the ACP authors added. Advance care planning is also crucial, but “patients generally wait for the physician to initiate” these discussions.

Nor should physicians be overly concerned about privacy laws like the Health Insurance Portability and Accountability Act (HIPAA), which states that health professionals “may share relevant health

care information with the family caregiver if the patient agrees to, or does not object to, the disclosure,” the authors pointed out.

The paper also emphasizes the need to provide emotional support to family caregivers. “Caregivers experience significantly less depression when the physician listens to their needs and concerns, and validates the importance of the caregiving role,” the authors wrote. Physi-

cians should “be alert for signs of distress ... and suggest appropriate referrals.”

“Medical schools are emphasizing new models of care and medical ethics more than ever before, but will need to continue to evolve programs to address these issues,” Dr. Hood said. “Caregivers do not always feel valued by the doctors. We as physicians need to recognize and acknowledge the enormous importance of family caregivers’ contributions to

the patient’s well-being, as well as the caregivers’ own stresses and needs, and work to improve communications.” ■

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