





FAMILY CAREGIVERS, P

How to cite this paper:

Mitnick S, Leffler, C, and Hood VL, for the American College of Physicians Ethics, Professionalism and Human Rights Committee. Family caregivers, patients and physicians: ethical guidance to optimize relationships. J Gen Intern Med. 2010; DOI 10.1007/s11606-009-1206-3. Available on SpringerLink at: <http://www.springerlink.com/openurl.asp?genre=article&id=doi:10.1007/s11606-009-1206-3>.

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## Abstract

Family caregivers play a major role in maximizing the health and quality of life of more than 30 million individuals with acute and chronic illness. Patients depend on family caregivers for assistance with daily activities, managing complex care, navigating the health care system, and communicating with health care professionals. Physical, emotional and financial stress may increase caregiver vulnerability to injury and illness. Geographically distant family caregivers and health care professionals in the role of family caregivers may suffer additional burdens. Physician recognition of the value of the caregiver role may contribute to a positive caregiving experience and decrease rates of patient hospitalization and institutionalization. However, physicians may face ethical challenges in partnering with patients and family caregivers while preserving the primacy of the patient-physician relationship. The American College of Physicians in conjunction with ten other professional societies offers ethical guidance to physicians in developing mutually supportive patient-physician-caregiver relationships.

## Introduction

Family caregivers in the United States provide care for about 90 percent of dependent community-dwelling individuals with acute and chronic physical illness, cognitive impairments and mental health conditions (1-3). Family caregivers as defined here include relatives, partners, friends and neighbors who assist with activities of daily living and complex health care needs that were the domain of trained hospital personnel (4,5). Approximately 30 – 38 million family caregivers over the age of 18 helped patients manage illnesses and treatment recommendations in 2006 (6). They expedite evaluation and may prevent medical errors and inefficiencies in our fragmented health care system. In addition, caregivers navigate often overwhelming health insurance system and communicate with multiple health care professionals. Coping with physical, emotional, spiritual and financial challenges affects caregiver health and quality of life as well as patients' health and quality of life.

Although hospice and palliative care address the impact of illness on both patients and families, historically the patient-physician relationship has focused on the patient and his or her rights and interests with less attention to the patient's experience within the context of his or her family and social relationships. Contemporary bioethics, with its emphasis on patient autonomy and confidentiality has supported this model but is beginning to recognize the need for a family-centered approach. Caregivers require information, access to resources and support to facilitate their role. Physicians can positively affect the caregiving experience by recognizing and addressing caregivers' physical, psychological, spiritual and emotional needs and acknowledging the value of the caregiver role.

Integrated health care models such as the Advanced Medical Home model directs physicians to "create an integrated, coordinated plan for ongoing medical care in partnership with patients and their families" (7). Physicians who adopt this approach are poised to extend the key attributes of this model to patients and their caregivers. However, an expanded patient-physician-caregiver relationship may present ethical challenges. The American College of Physicians in conjunction with ten other professional societies offers the following ethical guidance in hopes of fostering mutually supportive patient-physician-caregiver partnerships and stimulating further research.

## Development Process

An initial draft of a statement developed by the ACP Center for Ethics and Professionalism staff and members of the ACP Ethics, Professionalism and Human Rights Committee was discussed and subsequent revisions were made through December 2007. The draft underwent internal review by the ACP Board of Governors and ACP Councils, followed by external peer review. The paper was revised and then approved by the ACP Board of Regents in 2008. The statement was endorsed by ten medical professional societies: Society of General

The physician's obligation to respect the patient's decision-making rights and privacy and provide the caregiver with adequate information can be challenging. Physicians should give patients adequate opportunity to address confidential matters in private. These private exchanges can be especially important for addressing concerns about whether a caregiver is acting in the patient's best interests. Private exchanges may include determining whether the patient feels safe and well cared for; eliciting fears or concerns; obtaining the names of other family caregivers the patient might want the physician to contact; and determining whether the patient requires legal or social services. Patients should be evaluated for neglect and physical, emotional or financial abuse apart from the caregiver or family members. Physicians must be familiar with specific state reporting statutes and the implications of reporting patient neglect or abuse.

Physician accessibility and excellent communication are fundamental to supporting the patient and family caregiver.

The physician should strive to ensure that the patient, family caregiver and other family members have a common, accurate understanding of the patient's condition and prognosis.

Caregivers cite access to clear, consistent, understandable information about the patient's medical condition and treatments as the single most pressing unmet need during ICU hospitalizations (16). Physicians believe they provide far more information to 6(e)-.6(1735is ))TJ 4 8.



adult patient. Patients generally wait for the physician to initiate advance care planning discussions (22). Physicians must always be sensitive to cultural and family values, and should respect family approaches to decision-making where applicable (23). Declining health and advanced age mark important opportunities to solicit decision-making preferences, discuss health care values with the patient and family and allow all to gain a



Physicians should recognize that geographically distant caregivers may face unique challenges.

The number of long distance family caregivers, defined as those who provide care from more than an hour from the family member, is increasing (41). Although limited data on this population are available, research suggests that these caregivers face additional burdens (45). In addition to measures that support all caregivers (e.g., reassurance that the health care team wants to achieve what is best for the patient; providing clear information on the patient's condition, prognosis and care plan; establishing a communication plan for keeping the caregiver informed), the physician should identify

When death occurs, the physician should personally communicate with the family caregiver, answer questions, and acknowledge death and its significance (22). Cultural sensitivity is particularly important (54,55). When a patient dies after a long hospitalization or course of illness, the physician should consider follow-up communication with the caregiver through a phone call or condolence note (18). This support of the family caregiver may improve bereavement outcomes (18), however, signs of significant depression or complicated grief may require a referral for intervention.

When the caregiver is a healthcare professional, the physician should draw appropriate boundaries to ensure that the caregiver is not expected to function in a professional capacity in relation to the patient and that the caregiver receive appropriate support, referrals and services.

Although limited data exist (56), anecdotal literature suggests that when the family caregiver is a health professional, caregiving may bring added unique pressures and ethical challenges (57-60). Any assumptions regarding level of medical knowledge of the patient's specific condition or technical and emotional ability to accurately assess treatment options may be problematic. The treating physician should assist in setting reasonable patient and family expectations re

## Acknowledgement

The ACP Ethics, Professionalism and Human Rights Committee would like to thank and acknowledge the following reviewers of this position paper who provided valuable insights and suggestions: Robert M. Arnold, MD, FACP; David J. Casarett, MD, MA; Lynn Friss Feinberg, MSW; Edward W. Honsinger, Jr, MD MACP; Carol Levine, MA; Solomon Liao, MD; Rhonda Richards; Lisa Saunders; Melvyn L. Sterling, MD, FACP; and Brenda Sulick, Ph.D.

## Conflict of Interest

Cathy Leffler receives royalties from Spri



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