

Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships

**American College of Physicians
Ethics, Professionalism and
Human Rights Committee
Position Paper 2009**

FAMILY CAREGIVERS, PATIENTS AND PHYSICIANS: ETHICAL GUIDANCE TO OPTIMIZE RELATIONSHIPS

Position Paper of the American College of Physicians

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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 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 once 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 the 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, coherent 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 Internal Medicine, American Academy of Neurology, American Academy of Hospice and Palliative Medicine, American College of Chest Physicians, American College of Osteopathic Internists, the American Geriatrics Society, American Medical Directors Association, American Thoracic Society, Society of Critical Care Medicine and the Endocrine Society.

Ethical Guidance

Respect for the patient's dignity, rights and values should guide all patient-physician-caregiver interactions.

Clinical encounters should be patient-centered, allowing for maximum appropriate patient autonomy and participation in decision-making.

Family caregivers have become an integral part of the health care system, working in partnership with patients and health care professionals. Patients may rely on their family caregivers for support in negotiating physician interactions. Family caregivers may view themselves as partners with the physician in the care of the patient, especially as the patient's illness progresses and the caregiver's role increases (8). In this situation, there is a risk that communication about care will shift prematurely to the caregiver, even though the patient is capable of making decisions. The focus should remain on the patient. Studies confirm that patients with mild to moderate cognitive impairment want to be involved in decisions about their care and can make valid statements of wishes, values and preferences (9-11). The health preferences of patients can evolve over time, and seriously ill patients rate their health status better than their surrogates or physicians (12). These studies further support patients' ongoing participation in decisions about their care. However, while some patients may prefer to participate in decisionmaking, others may wish to defer decisions to the caregiver. Physicians should assist family caregivers to maintain the dignity and autonomy of their loved ones (13).

The physician should routinely assess the patient's wishes regarding the nature and degree of caregiver participation in the clinical encounter and strive to provide the patient's desired level of privacy.

According to the Health Insurance Portability and Accountability of 1996 Act (HIPAA), health professionals may share relevant health care information with the family caregiver if the patient agrees to, or does not object to, the disclosure. HIPAA should not be viewed as a barrier to communication (14,15).

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 caregivers than caregivers believe they receive (17). However, physicians use of medical jargon and technical terminology can be confusing to family members (18). The attitude and language used in communicating information can be crucial to maintaining trusting relationships between families and physicians in the critical care (19) and other settings. Adequate information generates feelings of preparedness and confidence and sets the stage for success and cooperation (20).

When a competent patient and a family caregiver disagree regarding a decision, the physician should verify they have a common understanding of the patient's condition and prognosis and the patient's goals for care (21,22). Then, each option can be reviewed to determine to what extent it contributes to achieving the patient's goals balanced by the impact it will have on the caregiver. Patients have the right to make decisions regarding their medical treatment, but they may need to consider other caregiving alternatives if the burden of those decisions is too much for the family caregiver. Conflicts about treatment decisions may stem from disagreement about treatment risks or goals, or from the implications of a treatment for the caregiver. The physician may wish to refer the patient and caregiver(s) for assistance or counseling when conflicts persist.

Physicians should encourage discussion of the patient's health care values and advance care planning so the family caregiver and physician have a clear understanding of the patient's wishes.

Advance care planning facilitates implementing patient wishes and surrogate decision making. This planning should be part of routine preventive medical services with every

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 deeper understanding of beliefs and goals. This dialogue will better prepare the clinician and caregiver for decision making in the event it becomes necessary (24). Early indications of dementia accelerate the need to identify surrogate decision makers, clarify end-of life care preferences and discuss legal and financial matters (25). Advance directives enable patients to instruct others about their health care, end of life care, and decision-making preferences. The living will is an advance directive that specifies one's medical treatment wishes. The medical power of attorney, or durable power of attorney, another type of advance directive, identifies the person the patient has empowered to make health care decisions if needed. Physicians should encourage the patient to inform key family members and friends about end-of-life preferences. Physicians should also discuss making advance directives accessible to clinicians in all care settings including placement in the medical record (26).

Discussions that focus on cultural beliefs, values, goals and outcomes rather than on the desire for particular interventions and treatments contribute to a more satisfactory decision-making process (27). Identification of comfort-oriented interventions can calm fears and ease guilt associated with decisions to withhold or withdraw life-prolonging treatments (22,28). Physicians can help surrogates with feelings of guilt and anxiety that may impede decision making at the end of life by stressing that decisions should be based on patient values (18,29,30). If a physician cannot reach consensus with a patient and/or surrogate, he or she should arrange an ethics consultation and if appropriate, transfer care to physicians who are more receptive to the patient's or surrogate's wishes (31,32).

The physician should recognize the value of family caregivers as a source of continuity regarding the patient's medical and psychosocial history and facilitate the intellectual and emotional transition to the end stage of serious chronic illness.

Physicians should routinely validate the family caregiver's role and be sensitive to specific commitments the caregiver may have made regarding how he or she will manage the patient's care.

Caregivers are valuable members of the health care team, helping patients manage and cope with illness. Patient information provided by the caregiver may be as pertinent and reliable as the medical record. Acknowledgement of the caregiver contribution is vital to ongoing trust and continued collaboration providing patient care. The degree to which family caregivers feel supported by the physician may influence the caregivers' burden, attitude, and emotional health status (33). In turn, their ability to provide care affects patients' health, rates of hospitalization, and long-term care placement (34). Caregivers experience significantly less depression when the physician listens to their needs and concerns, and validates the importance of the caregiving role (18,35).

Caregiver concerns about failing to meet expectations to manage care cause significant stress that can impede decision-making regarding end-of-life care, utilization of outside services and institutional placement (36). As the patient's condition evolves, the physician can help the caregiver understand the role of additional services in improving the health and quality of life for both the patient and the caregiver. This issue may need to be revisited as the patient's care becomes more complex and the demands on the caregiver increase (20,37).

Physicians should develop care plans that are patient-specific and caregiver-specific and provide information, training and referrals to support those plans.

During office visits or hospitalizations, physicians should assess caregivers' well-being and concerns in order to identify needs for education and social service referrals, future patient placement or respite care (38,39). Complex care and symptom management at home requires training and support. In addition to technical aspects of care, for example, parental administration of medication, caregiver education also includes identification and management of treatment side effects, nonpharmacologic symptom management and signs of advancing disease.

The physician should be alert for signs of distress in the family caregiver and suggest appropriate referrals.

Family caregivers face overwhelming physical, emotional and financial demands that may make them especially vulnerable to injury, depression and other stress-related conditions (40). Caregiving may cause caregivers' health to decline (41) and negatively affect their ability to provide care (42). The Caregiver Health Effects Study demonstrated a strong link between caregiving and mortality risk, finding that strained elderly caregivers supporting disabled spouses at home were 63 percent more likely to die within four years than non-caregiving elderly spouses (43).

Family caregivers often lack the time and energy to prepare meals, exercise, or obtain their own recommended preventive medical care (42). Recent studies of caregiver support indicate that interventions that encourage and facilitate self-care and social enjoyment have a positive impact on caregiver quality of life (44). The physician should stress the importance of caregiver self-care for the benefit of both the caregiver and the patient and identify appropriate sources of community support services, such as home health aides, respite or adult day care. Referrals to support groups, training and community and social services, can help sustain successful caregiving (38).

When a family caregiver is also a patient of the treating physician, the physician should limit "curbside consults" and encourage separate appointments to focus on the needs of the caregiver or the patient. In order to ease the burden on the caregiver, appointments may occur in tandem but not simultaneously.

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 the patient's local support system, and make referrals for service providers such as geriatric care managers, social services and home health agencies to create a system the caregiver can utilize as needed (46).

The physician should define a palliative care plan that focuses on maximizing patient and caregiver quality of life.

Hospice and palliative care are often seen as interchangeable, but the goal of palliative care services is to prevent and relieve suffering and support the best possible quality of life for patients and their families regardless of disease stage (47). Early access to the services of a comprehensive palliative care team can significantly reduce the burden of illness and optimize functioning and coping for both patients and caregivers. Patients and their caregivers may need reassurance that palliative care can be integrated with treatment of incurable chronic disease (25).

Hospice may be considered appropriate for patients with a life expectancy of six months or less (48). At this point, the physician must gently guide the patient, caregiver and family toward the realization that cure is no longer a realistic goal of care (49). Open discussion of the reality of the progressive condition is crucial to earlier access to hospice enrollment, either at home, in the hospital, or in a freestanding facility. This will allow caregivers and families the opportunity to make final arrangements, resolve differences, reach closure and say goodbye (19). The caregiver who receives preparation for the final phase of illness will be less likely to experience anxiety, depression or complicated grief after the patient dies (50).

The physician should monitor family caregivers for distress due to issues of loss during the period leading up to and after the death of the patient.

The physician can ease the burden of the grieving process by ensuring that the caregiver has received adequate support in the caregiving role and is prepared for the patient's death. When death is preceded by a long period of intense successful caregiving, the caregiver often experiences fewer negative effects (51). The period of decline can allow the caregiver to grieve, prepare and say goodbye (52). Interventions to address anticipatory grief, such as open discussions of the anticipated loss and plans for the future, are especially appropriate for caregivers (53).

When death occurs, the physician should personally communicate with the family caregiver, answer questions, and acknowledge the loss 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 or 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 regarding the caregiver's role in interpreting disease processes, prescribing medications, dealing with new symptoms, etc. Patients and family members need to be informed that it is generally not appropriate for physician caregivers to treat family members and they should not place the physician-caregiver in compromising emotional and professional positions in non-emergent situations (26).

The physician-caregiver should be careful not to function as, or appear to be, a treating physician. However, he or she can facilitate and improve communication between the treating physician, the patient, and other family members as well as assist in monitoring and delivering care as directed by the treating physician. In this role, the physician-caregiver can improve continuity of care and ameliorate the many potential adverse consequences of the fragmented medical system.

Conclusion

The ethical guidance outlined in this paper is intended to heighten physician awareness of the importance and complexity of the patient-physician-family caregiver relationship, to maximize the benefits of those relationships and to minimize the burdens on family caregivers. This guidance builds on general principles of medical ethics and professionalism, extending them to family caregivers for the benefit of the patients. An appendix of resources related to family caregivers is available online to assist physicians in implementing these principles to build effective partnerships with family caregivers.

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; Richard W. Honsinger, Jr, MD MACP; Carol Levine, MA; Solomon Liao, MD; Rhonda Richards; Linda Saunders; Melvyn L. Sterling, MD, FACP; and Brenda Sulick, Ph.D.

Conflict of Interest

Cathy Leffler receives royalties from Springer Publishing for: Leffler, C. Patient and medical education on complementary and alternative care: sorting it all out. In Snyder L ed. Complementary and Alternative Medicine: Ethics, the Patient and the Physician. Totowa, NJ: Humana Press Inc. 2007. Dr. Hood receives grant funding for Best Practices in Managing Hypertension Learning Collaborative, American Medical Group Association with support from Daiichi Sankyo. No other conflicts of interest were disclosed.

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