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

This paper, written by Sheryl Mitnick, MPH, RN, Cathy Leffler, JD, and Virginia L. Hood, MBBS, MPH, FACP, was developed by the American College of Physicians (ACP) Ethics, Professionalism and Human Rights Committee. Members of the Committee were Virginia L. Hood, MBBS, MPH, FACP (Chair); Joseph J. Fins, MD, FACP (Vice Chair); Clarence H. Braddock, III, MD, MPH, FACP; Neil J. Farber, MD, FACP; Thomas H. Gallagher, MD, FACP; Richard A. Hranac, MD, FACP; Diane E. Meier, MD, FACP; Aliza Monroe-Wise, MSc; Alejandro Moreno, MD, FACP; Paul S. Mueller, MD, MPH, FACP; Richard L. Neubauer, MD, FACP; Shakaib U. Rehman, MBBS, FACP; Mahmoud Sharaf, MD; Mehdi C. Shelhamer, DO; Barbara J. Turner, MD, FACP; and Frederick E. Turton, MD, FACP. The paper was approved by the ACP Board of Regents on July 13, 2008. The paper has also been endorsed by the Society of General Internal Medicine, the American Academy of Neurology, the American Academy of Hospice and Palliative Medicine, the American College of Chest Physicians, the American College of Osteopathic Internists, the American Geriatrics Society, the American Medical Directors Association, the American Thoracic Society, the Society of Critical Care Medicine and The Endocrine Society.

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.

For questions about the content of this Position Paper, please contact ACP,
Center for Ethics and Professionalism, 190 N. Independence Mall West,
Philadelphia, PA 19106. Telephone 215-351-2400. To order copies of this Position Paper, contact ACP Customer Service at 800-523-1546 extension 2600, or 215-351-2600

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.

References

1. Feinberg, LF. Options for supporting family caregivers. A policy paper of the Family Caregiver Alliance. 1997.
2. Carol Levine. Introduction to Family Caregiving: Current Challenges for a Time Honored Practice. Generations (J. Amer. Soc. On Aging) Winter 2003-2004; 27:5-8
3. Family Caregiver Alliance, National Center on Caregiving. Caregivers count too! A toolkit to help practitioners assess the needs of family caregivers. June 2006. Available at: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695. Accessed November 11, 2009.
4. Levine C, Reinhard SC, Feinberg LF, Albert S, Hart A. Family caregivers on the job: moving beyond ADLs and IADLs. Generations (J. Amer. Soc. On Aging) Winter 2003-2004; 27: 17-23.
5. Gould DA. Family caregivers and the health care system. Findings from a National Survey. In The Cultures of Caregiving. Conflict and Common Ground among Families, Health Professionals and Policy Makers. Levine C. and Murray TH. Ed.2004 Baltimore: The Johns Hopkins University Press.
6. Gibson MJ, Houser AN. (2007). Valuing the invaluable: A new look at the economic value of family caregiving. Washington, D.C.: AARP Public Policy Institute.
7. Barr M, Ginsburg J. The advanced medical home: a patient-centered, physician-guided model of health care. Policy monograph. American College of Physicians: 2006. Available at: http://www.acponline.org/advocacy/where_we_stand/policy/adv_med.pdf. Accessed November 11, 2009.
8. Glasser M, Prohaska T, Gravdal J. Elderly patients and their accompanying caregivers on medical visits. Research on Aging. 2001;23:326-348.
9. Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JHT. Do Alzheimer's Disease patients want to participate in a treatment decision, and would their caregivers let them? Gerontologist 2005;45:381-388.
10. Fact Sheet : Helping Families Make Everyday Care Choices (for Providers). Family Caregiver Alliance 2000.. Available at: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=405. Accessed November 11, 2009.
11. Whitlatch CH, Feinberg LF, Tucke SS. Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. Gerontologist. 2005;45:370-380.
12. Tsevat J, Cook EF, Green ML, et al. Health values of the seriously ill. Ann Intern Med. 1995;122:514-520.
13. Levine C. The good doctor: the carer's perspective. Clin Med. 2004;4(3): 244-245.
14. 45CFR164.510
15. Wilson, JF. Health Insurance Portability and Accountability Act Privacy rule causes ongoing concerns among clinicians and researchers. Ann Int Med. 2006 Aug 15;145(4):313-6
16. Auerbach SM, Kiesler DJ, Wartella J, Rausch S, Ward KR, Ivatury R. Optimism, satisfaction with needs met, interpersonal perceptions of the healthcare team, and emotional distress in patients' family members during critical care hospitalization. Am J Crit Care. 2005;14:202-210.
17. Alzheimer's Association. Alzheimer's Disease Study: Communication Gaps Between Primary Care Physicians and Caregivers. May 2001. Available at: http://www.alz.org/national/documents/alzheimerreport.pdf. Accessed November 11, 2009.
18. Rabow MW, Hauser JW, Adams J. Supporting family caregivers at the end of life. "They don't know what they don't know." JAMA. 2004;291:483-491.
19. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? J Palliat Med. 2005;8:1176-1185.
20. Ronch JL. Changing institutional culture: turning adversaries into partners. In The Cultures of Caregiving. Conflict and Common Ground among Families, Health Professionals and Policy Makers. Levine C. and Murray TH. Ed. 2004 Baltimore The Johns Hopkins University Press.
21. Kaldjian LC, Curtis AE, Shinkunas LA, Cannon KT. Goals of care toward the end of life: a structured literature review. American Journal of Hospice and Palliative Medicine 2009; 25: 501-511.
22. von Gunten, Ferris FD, Emanuel LL. Ensuring competency in end-of-life care. Communication and relational skills. JAMA. 2000;284:3051-3057.
23. Crawley LM., Marshal PA, Koenig BA. Respecting cultural differences at the end of life. In Snyder L. and Quill T. Eds. Physician's Guide to End of Life Care. Philadelphia: American College of Physicians; 2001:35-55.
24. Rodriquez KL, Young AJ. Perspectives of elderly veterans regarding communications of medical providers about EOL Care. J Palliative Med. 2005;8:534-544.

25. Covinsky KE, Yaffe K. Editorial Dementia, prognosis and the needs of patients and caregivers. Ann Intern Med. 2004;140:573-574.
26. Ethics and Human Rights Committee, American College of Physicians. Ethics manual: fifth edition. Ann Intern Med. 2005;142:560-82. Available at: http://www.acponline.org/running_practice/ethics/manual/. Accessed on November 11, 2009.
27. Perkins HS. Controlling Death: The false promise of advance directives. Ann Int Med. 2007;147:51-57.
28. Karlawish JH, Quill TE, Meier DE. A consensus-based approach to practicing palliative care for patients who lack decision-making capacity. In Snyder L. and Quill T. Eds. Physician's Guide to End of Life Care. Philadelphia: American College of Physicians; 2001:19-34.
29. Fins JJ, Maltby BS, Friedmann E, et al. Contracts, Covenants and Advance Care Planning: An Empirical Study of the Moral Obligations of Patient and Proxy. J Pain Symptom Manage. 2005;29(1): 55-68.
30. Fins JJ, Maltby BS. "Fidelity, Wisdom, and Love: Patients and Proxies in Partnership." New York: Fan Fox and Leslie R. Samuels Foundation. 2003.
31. Lang F, Quill T. Making decisions with families at the end of life. Am Fam Physician. 2004;70:719-723.
32. Quill TE, Byock IR. Responding to intractable suffering: the role of terminal sedation and voluntary refusal of food and fluids. Ann Intern Med. 2000;132: 408-414.
33. Parks SM, Novielli KD. A practical guide to caring for caregivers. Am Fam Physician. 2000; 62(12):2613-22.
34. Coleman EA, Parry C, Chalmers S, Min S. The care transitions intervention: results of a randomized controlled trial. Arch Intern Med. 2006;1 66(17):1822-1828.
35. Musil CM, Morris DL, Warner CB, Saeid H. Issues in Caregivers' stress and providers' support. Research on Aging 2003;25:505-526.
36. Mezey M. Nurses and their changing relationship to family caregivers. In The Cultures of Caregiving. Conflict and Common Ground among Families, Health Professionals and Policy Makers. Levine C. and Murray TH. Eds. 2004 Baltimore: The Johns Hopkins University Press.
37. Brazil K, Bedard M, Krueger P, Abernathy T, Lohfeld L, Willison K. Service preferences among family caregivers of the terminally ill. J of Palliative Med. 2005;8:69-78.
38. Given BA, Given CW, Kozachik S. Family support in advanced cancer. CA Cancer J Clin. 2001;51:213-231.
39. Levine C, Murray TH. Conclusion. Building on Common Ground. In The Cultures of Caregiving. Conflict and Common Ground among Families, Health Professionals and Policy Makers. Levine C. and Murray TH. Eds. 2004 Baltimore: The Johns Hopkins University Press.
40. Dern A, Heath A. Reaching out to caregivers through physicians. Generations (J. Amer. Soc. On Aging) Winter 2003-2004; 27:84-86.
41. National Alliance for Caregiving and AARP. Caregiving in the US. April 2004. Bethesda, MD and Washington, DC. Available at: http://www.caregiving.org/data/04finalreport.pdf. Accessed November 11, 2009.
42. Evercare and The National Alliance for Caregiving. Evercare study of caregivers in decline: a close-up look at the health risks of caring for a loved one. September 2006. Minnetonka, Minnesota. Available at: http://www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf. Accessed November 11, 2009.
43. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the caregiver health effects study. JAMA. 1999;282:2215-2219.
44. Belle SH. et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups; a randomized, controlled trial. Ann Intern Med. 2006;145:727-738.
45. Benefield LE and Beck C. Reducing the distance in distance-caregiving by technology innovation. Clin Interv Aging(2007); 2(2): 267--272.
46. Karlawish J, Quill TE, Meier D for the ACP-ASIM End-of-Life Care Consensus Panel. A consensus-based approach to providing palliative care to patients who lack decision-making capacity. Ann Intern Med. 1999;130: 835-40.
47. American Academy of Hospice and Palliative Medicine. Definition of Palliative Care. Available at http://www.aahpm.org/positions/definition.html. Accessed November 11, 2009.
48. United States Department of Health and Human Services. Centers for Medicare & Medicaid Services. Medicare Hospice Benefits. CMS Publication No. 02154 Revised September 2008. Available at: http://www.medicare.gov/publications/Pubs/pdf/02154.pdf. Accessed November 11, 2009.
49. Bascom PB, Tolle SW. Care of the family when the patient is dying. West J Med. 1995;163:292-296.
50. Hebert RS, Dang Q, Schulz R. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. J Palliat Med. 2006; 9,3:683-93.

51. Schulz R, Mendelsohn AB, Haley WE, et al. End-of-life Care and the effects of bereavement on family caregivers of persons with dementia. N Engl J Med. 2003; 349:1936-1942.
52. Schulz R, Beach SR, Lind R, et al. Involvement in caregiving and adjustment to the death of a spouse. Findings from the Caregiver Health Effects Study. JAMA. 2001; 285:3123-3129.
53. Cassarett D, Kutner JS, Abrahm J. Life after death: a practical approach to grief and bereavement. In Snyder L. and Quill T. Eds. Physician's Guide to End of Life Care. Philadelphia: American College of Physicians, 2001:178-193.
54. Crawley LM, Marshall PA, Lo B, Koenig BA, End-of-Life Care Consensus Panel. Strategies for culturally effective end-of-life care. *Ann Intern Med.* 2002;136(9):673-679
55. Lo B, Quill T, Tulsky J. Discussing palliative care with patients. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians-American Society of Internal Medicine. Ann Intern Med. 1999;130:744-9.
56. Wasserman RC, Hassuk BM, Young PC, Land ML. Health Care of Physicians' Children. Pediatrics 1989; 83: 319-322.
57. Wahls TL. Reflections: A Daughter's Duty. JGIM 2008; 23(6): 887-888.
58. Sirmon MD. Tobacco, tulips, and terminal care. Ann Intern Med 1993; 1042-1043. Available at: http://www.annals.org/content/119/10/1042.full. Accessed November 11, 2009.
59. Southwick F. Who Was Caring for Mary? Ann Intern Med 1993; 146-148. Available at: http://www.annals.org/content/118/2/146.full. Accessed November 11, 2009.
60. Chen FM, Feudtner C, Rhodes LA, Green LA. Role conflicts of physicians and their family members: rules but no rulebook. West J Med. 2001; 175(4): 236–239.