

Physicians can help family members caring for dying loved ones

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Physicians have five areas of opportunity to be of service to family members caring for patients at the end of life, according to a UCSF Medical Center palliative care expert.

The recommendations appear in the January 28, 2004 issue of the Journal of the American Medical Association (JAMA), in a section titled Perspectives on Care at the Close of Life, co-edited by UCSF clinician/researchers.

These interventions include promoting good communication with family members, encouraging appropriate advance care planning and decision-making, supporting home care, demonstrating empathy for family emotions and relationships, and attending to family grief and bereavement.

"In caring well for family caregivers at the end of life, physicians may not only improve the experiences of patients and family, but also find greater sustenance and meaning in their own work," said Michael Rabow, MD, an internal medicine and palliative care specialist at UCSF Medical Center. Rabow is the lead author of the new evidence-based discussion of a challenging palliative care case, titled Supporting Family Caregivers at the End of Life: They Don't Know What They Don't Know.

He explained that death in the United States is increasingly preceded by informal support and lay medical care provided by family members, partners and friends.

"About one quarter of adults in the United States report providing informal

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caregiving, including helping with transportation, shopping, house work, emotional support, nutritional care, personal care and financial management," he said.

"Because this trend is likely to continue because of the aging United States population and the increasing number of diseases managed over many years in outpatient settings, physicians need specific training in how to assist families with end-of-life care."

Given the documented financial, emotional and physical costs of family care giving, including increased mortality for caregivers, the authors have the following recommendations for physicians:

1) Listen carefully to family members and provide proactive guidance, particularly when the patient is no longer able to make decisions about his or her own health care. This includes sharing data on the efficacy of feeding tubes and cardiopulmonary resuscitation in relevant situations and explaining the role of hospice. Ultimately, physicians have a role in helping families come to understand what their loved one's medical care signifies "including the particular family's definitions of doing everything," "giving up," or "letting go," said Rabow.

2) Facilitate advance care planning. This may include discussion with the family members about preferences, values and goals for end-of-life care. Physicians can also encourage family members to explore legal advance directives, the naming of a health care proxy, the execution of a living will, and plans for autopsy, organ donation, funerals and disposition of possessions. Advance care planning is not a static document or set of instructions, but rather an ongoing process and an opportunity to engage with families and patients, he said.

3) Be part of the interdisciplinary home care team that provides caregivers with orientation, information, training and support. He explained that family caregivers are medical team representatives in the home, providing medical services and assessments, including complex decisions about when to call the physician or bring the patient to the Emergency Room - all with little preparation, training or compensation. Specifically, physicians should give caregivers careful instructions about medication and how to convey their loved one's wishes about advance care directives if it is necessary to call for emergency help, Rabow said. He added that physician home visits have been shown to improve patient quality of life and delay nursing home admissions.

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4) Have empathy for family emotions and relationships. In particular physicians must recognize that adult children frequently assume responsibilities for ill parents and may have to adjust the expectations within their own nuclear families, according to Rabow. He added that family members may find themselves re-acquainted with long-stranded relatives, which may also escalate emotions and strain relationships. Physicians can be helpful in recognizing and validating common feelings and helping family members identify necessary support services, said Rabow.

5) Pay special attention to grief and bereavement following death of a loved one. According to Rabow, grief worsens both physical and mental health and it has been associated with increased depression, insomnia, substance abuse, suicide and mortality in family members. He added that bereaved family members highly value a physician condolence telephone call, letter, or visit, as well as attendance at the patient's funeral and that this support may improve bereavement outcomes.

"Dame Cicely Saunders, a pioneer in the modern palliative care movement once said, 'How people die remains in the memories of those who live on,'" said Rabow.

"Given that observation, physicians have a special responsibility and a fundamental opportunity to support the profound experiences of family care giving."

Additional authors of these recommendations include Joshua Hauser, MD, from the Feinberg School of Medicine at Northwestern University and Jocelia Adams, RN, director of the Center for Caregiver Training in San Francisco.

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The JAMA series on end-of-life care is produced with the support of the Robert Wood Johnson Foundation. In addition to Rabow, the series is co-edited by Stephen McPhee, MD, UCSF professor of medicine and Steven Pantilat, MD, UCSF associate professor of medicine. JAMA section editor is Margaret Winker, MD.