

# Supporting Family Caregivers at the End of Life

## "They Don't Know What They Don't Know"

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### THE PATIENT'S STORY

Mr R was a 70-year-old man, legally blind from retinitis pigmentosa, who was diagnosed as having pancreatic cancer in January 2002. He underwent a Whipple procedure at an urban academic medical center and then received radiation therapy and chemotherapy with fluorouracil and gemcitabine. To alleviate intermittent bowel obstructions, he had a ventilating gastrostomy tube placed for decompression of his abdomen. Over the next 9 months, he was admitted to the hospital several times for infections at the site of his gastrostomy tube, diarrhea, vomiting, and dehydration.

He lived at home with his wife, Mrs R, who was also his partner in the marketing firm he had founded. He had one daughter, Ms L, a psychologist who lived locally, and a son, a history professor, who lived far away but visited every few weeks. Both children were active caregivers over the course of their father's illness. Despite Mrs R's own severe rheumatoid arthritis and other health issues, she was determined to care for her husband at home with the assistance of a home care nurse, Ms P, and a housekeeper to aid with daily chores.

As Mr R's health deteriorated, a close friend of Ms L's advised her about a local in-hospital palliative care unit. In November 2002, when Mr R's pain and nausea became so severe that they could not be managed at home, he was admitted to the palliative care unit. At admission, Mr R was alert and oriented but bed bound due to weakness. He and his family hoped his symptoms could be quickly controlled so that he could return home. He received intravenous hydromorphone and dexamethasone for pain and intravenous haloperidol and frequent gastrostomy tube flushings for his nausea. His symptoms initially improved and discussions ensued about his transition home. Although scheduled to go home with hospice care, his condition then declined rapidly to a point where his family did not think they could care for him at home, even with in-

Even for patients receiving complex, intensive medical care for serious and life-threatening illness, family caregiving is typically at the core of what sustains patients at the end of life. The amorphous relationship between physicians and the families of patients at the end of life presents both challenges and opportunities for which physicians may be unprepared. Families play important roles in the practical and emotional aspects of patient care and in decision making at the end of life. At the same time, family members may carry significant burdens as a result of their work. Through the perspectives of the wife, daughter, and home care nurse of a patient who died from pancreatic cancer, we illustrate the range of family caregiver experiences and suggest potentially helpful physician interventions. We describe 5 burdens of family caregiving (time and logistics, physical tasks, financial costs, emotional burdens and mental health risks, and physical health risks) and review the responsibilities of physicians to family caregivers. Based on available evidence, we identify 5 areas of opportunity for physicians to be of service to family members caring for patients at the end of life, including promoting excellent communication with family, 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.

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creased assistance. They struggled to find a balance between the level of nursing care he could receive in the palliative care unit and his initial desire to be at home. After 7 days in the palliative care unit, he died, with his family at his bedside.

## PERSPECTIVES

In December 2002, shortly after Mr R's death, a *Perspectives* editor separately interviewed Mr R's wife (Mrs R), daughter (Ms L), and home care nurse (Ms P).

**MRS R:** *I knew I would take care of him myself because we had always done things together. We worked together for 30 years. We played together, we did everything together since I was 18 years old. Because he had been legally blind since the early 1970s, I had always been by his side. There was never a question that I wouldn't continue to be [with him] during this period.*

**Ms L:** *I think that physicians need to be as aware as they can as to how alone and ignorant the family and the patient feel. For example, Dad's physician was sort of ominously saying with raised eyebrows, "The bilirubin is going up, the bilirubin is going up." But we had no context for that. We knew it was bad, but we didn't know if that meant that in 6 months he was going to be in trouble, or in a week he might be in trouble.*

**Ms P:** *When they go into the hospital, they become patients, but they're really people. In the hospital you can forget: they're all in the same kind of rooms; they're all in the same kind of gowns; they all have tubes and things hooked up to them. But at home, they're people. They're in their house, they're surrounded by their photographs, the things they've worked for all their life. They're people first, and then they're patients.*

As with Mr R, the story of a dying patient is often also a story about loving family members. Increasingly, death in the United States is preceded by family caregiving—informal support and lay medical care provided by family members, partners, and friends.<sup>1-5</sup> About one quarter of adults in the United States report providing informal caregiving,<sup>6</sup> including helping with transportation, shopping, home-making, emotional support, nutritional care, nursing care, personal care, and financial management.<sup>1,2,7,8</sup> Family members, almost always women, provide nearly all of the care patients receive at home.<sup>1,9</sup> The prevalence of chronic family caregiving is likely to increase with the aging US population and the increasing number of diseases managed over many years in the outpatient setting.<sup>10,11</sup>

In light of the pervasiveness and importance of family caregiving, the physician's relationship with family caregivers is an important facet of the patient-physician relationship. Mr R's illness richly illustrates both the joys and the challenges of family caregiving. We describe the burdens of family caregiving, outline basic physician responsibilities in the support of family caregivers, and identify 5 areas in which physicians can be of service to family members caring for patients at the end of life.

## BURDEN OF FAMILY CAREGIVING

### Time and Logistics

**MRS R:** *To me, it just never stopped. It wasn't the care, it was the whole commitment. It never went away.*

Caregiving can take as little as a few hours per week, but, commonly, it is equivalent to a full-time job, with 20% of caregivers providing full-time or constant care.<sup>6,12,13</sup> Mrs R reported spending about 10 hours a day tending to her husband, but the sense of responsibility was never-ending. The length of a patient's illness before death and the trajectory of functional decline (and concomitant caregiving need) are difficult to predict, particularly in noncancer conditions.<sup>14</sup> The administrative and logistical needs can be enormous: families typically must coordinate numerous medications, treatments, clinical and social services, as well as the needs of multiple family members. At times, families may feel as if they are "reinventing the wheel," with each individual family trying to identify local services even though many in their community have struggled with the very same issues.

### Physical Tasks

Laborious caregiving is often performed by people who are themselves elderly, ill, and disabled.<sup>6</sup> In this case, Mrs R has severe rheumatoid arthritis. Caregivers usually have no training in moving, lifting, or turning seriously ill adults, yet they routinely perform these strenuous physical activities. As a result, family caregivers are at significant risk of physical injury. Fortunately, Mrs R realized that her husband "couldn't move and I wasn't strong enough to help him" and asked her daughter and the nurse for help.

### Financial Costs

Caregiving creates an uncompensated financial burden for family members, both in outright expenses and in lost income and benefits.<sup>6,15</sup> In the United States, yearly family caregiving costs range from \$3 billion to \$6 billion for diabetes,<sup>4</sup> more than \$6 billion for stroke,<sup>16</sup> and \$65 billion for patients with Alzheimer disease.<sup>17</sup> The economic disruption of family caregiving can be profound: 20% of family caregivers must quit work or make major life changes and 31% lose most or all of their family savings as a result of caregiving.<sup>2</sup> African American and Hispanic caregivers are more likely to experience economic disruption compared with whites.<sup>18</sup> The economic burden is similar within both managed care and fee-for-service health care systems.<sup>19</sup> Government support for family caregiving is limited: the Family Medical Leave Act of 1993 guarantees only unpaid leave to care for a seriously ill spouse, son, daughter, or parent; only a few states allow those eligible for Medicaid's personal care benefit to receive a cash allowance to purchase their own care and hire friends or family to provide it.

Patients and family members may feel differently about the intense costs of caregiving. Patients often fear being a burden to their family, despite the family's willingness to provide care.<sup>20,21</sup> Family economic hardship is associated with

a preference for “comfort only” care over life-extending care.<sup>22</sup> Substantial caregiving needs have even been associated with an increased likelihood of patients considering euthanasia or physician-assisted suicide.<sup>23,24</sup>

### Caregiver Emotional Burdens and Mental Health Risks

Caregivers often bear an incalculable emotional burden for their work. Although many enjoy a profound sense of privilege and derive deep satisfaction in this role, sadness, guilt, anger, resentment, and a sense of inadequacy are also common and understandable reactions. Exhaustion, financial strain, disrupted usual activities, and continuous caregiving contribute to significant mental health morbidity, including anxiety and depression.<sup>25</sup> Although selection bias may lead to overestimates of the prevalence of caregiver depression, a number of studies document that as many as one half of all caregivers experience clinical depression, with 61% of intense family caregivers (those providing at least 21 hours of care per week) experiencing depression.<sup>26,27</sup> Caregiver wives appear to be more likely than caregiver husbands to have depression.<sup>28</sup>

### Health Risks for Caregivers

MRS R: *My health isn't red hot, but I didn't worry about it at all.*

Family caregivers tend to put the needs of the ill person ahead of their own, minimizing the severity of their own problems and forgoing or delaying their own health care.<sup>29</sup> Caregiving is associated with poor sleep<sup>30</sup> and even with increased cancer risk.<sup>31</sup> Caregivers are at particular risk for worsened health if they have poor baseline health or limited education and if caregiving means significant loss of social and leisure time.<sup>5,32</sup> Notably, caregiving is also associated with increased caregiver mortality.<sup>8</sup> In a 4-year study of 392 caregivers and 427 noncaregivers older than 66 years, caregivers who experienced mental or emotional strain had a mortality risk 63% higher than noncaregiving controls.<sup>33</sup>

### THE PHYSICIAN'S RESPONSIBILITIES TO FAMILY

Given the significant risks of family caregiving and the goal of comprehensive patient care, physicians clearly have a role to play with the families of patients at the end of life. In clinical practice, however, physicians may be uncertain about their relationship and responsibility to the family. Sensitive negotiating family issues can be difficult for physicians, but it is intensified when families challenge the physician's authority, are plagued by their own disagreements, raise the specter of litigation, or are culturally or religiously diverse from the physician.<sup>34,35</sup> Physicians also must be alert to the fact that their own patients, even those with advanced illness, may actually be serving as the caregiver for even more seriously ill relatives.<sup>36,37</sup>

A physician's legal obligation is to the patient; legal obligations to the family are minimal. Physicians are required to address the wishes of appropriate patient surrogate decision makers and to report patients they believe are being abused

or neglected. However, the physician's role should extend beyond what is required by law to provide the best possible care for the patient. The Council on Scientific Affairs of the American Medical Association argues that family caregivers and physicians are interdependent and should create a care partnership.<sup>38</sup> The patient's primary care physician has a key linkage role, assessing the caregiver as well as the patient in a comprehensive home-based approach that includes training caregivers, validating the caregiver's role, and case management.<sup>38</sup> Physicians must recognize that family caregivers provide an instrumental component of patient care and support them sufficiently. Physicians can assess family caregivers with a simple screening question such as, “How is the caregiving going for you?” or “How is the family doing?” Vulnerable caregivers should be evaluated for their ability to provide care without putting their own health at risk,<sup>5,39</sup> and physicians should refer overwhelmed caregivers to support services and to the caregiver's own physician. Even well-meaning hospitalists and palliative care specialists can contribute to discontinuity of medical care at the end of life, and all clinicians must pay particular attention to ensuring clear communication with each other and with family during hand-offs between physicians and across care settings.<sup>40</sup>

### PHYSICIAN OPPORTUNITIES TO SERVE FAMILIES

Beyond the basic responsibilities, working both individually and as part of an interdisciplinary team, there is great potential for physicians caring for patients at the end of life to provide important and perhaps even life-sustaining support to family caregivers. Empirical research and the clinical experiences of experts suggest that there are at least 5 areas of service that physicians may offer to families.

### Excellent Communication With Family

MRS R: *[We moved him] almost more to avoid having to worry about not having a doctor who we could talk to than because he was in such bad shape.*

Ms L: *It's always hard to present a family with all of the gory details. [Although my mother did not], I personally would have wanted a clearer sense of perspective about the actual prognosis.*

Families want to know that their loved one's physician is comfortable talking about death and dying.<sup>41</sup> The needs of family members for timely and clear information<sup>42</sup> are significant but are frequently underappreciated.<sup>1,21</sup> Communication with families is complex due to the multiplicity of perspectives held by family members, as Ms L's observation makes clear. Physicians should provide proactive guidance, particularly when the patient is no longer able to make decisions about his or her own health care, including sharing data on the efficacy of feeding tubes and cardiopulmonary resuscitation in relevant situations, describing the possibility and process of withdrawal of interventions, and explaining the role and benefits of hospice.<sup>3,43,44</sup> Recently, using a large population-based sample of elderly persons,

hospice was associated with a significant reduction in the risk of death of the hospice patient's bereaved spouse, even when hospice was used only for a median of 3 to 4 weeks.<sup>45</sup>

Careful listening is paramount for physicians to understand the diverse perceptions family members may have regarding decisions about life-sustaining treatment, dying at home, and talking about the meaning of death.<sup>21</sup> Physicians can elicit a family's views with open-ended queries,<sup>46</sup> providing answers to a family's cognitive questions, but offering empathetic responses to their primarily affective expressions.<sup>47,48</sup> 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.<sup>49</sup>

Informal family communication may occur spontaneously at the bedside, in clinic, in the hallways of hospitals or nursing homes, or by telephone. Formal communication typically occurs in a family meeting or conference.<sup>50</sup> With appropriate documentation in the medical record, physicians can bill for this service, particularly if it takes place in the presence of the patient. Time spent can be used to determine the evaluation and management coding level if more than 50% of the encounter is spent counseling and relaying information. Family meetings take on increased importance at the end of life because many patients have lost their decision-making capacity.<sup>49,51</sup> Recommendations for conducting productive family meetings are presented in the Box. There are limited data about the efficacy of family meetings but one study of intensive family communication showed a 1-day reduction in median length of stay in the intensive care unit among patients who died.<sup>52</sup>

The Health Insurance Portability and Accountability Act (HIPAA) has generated significant concern among physicians with regard to privacy regulations, but the impact of HIPAA on physician-family communication is not yet known. As before, some have urged physicians to try to obtain patients' consent when talking with family members,<sup>53</sup> but this consent may often be presumed. The Office of Civil Rights Privacy Rule, as well as interpretation from the Web site of the Department of Health and Human Services, suggest that unless individuals have indicated that they do not want information shared with family members, HIPAA regulations allow it.<sup>54,55</sup> However, to provide good patient-centered care, for patients who are able, physicians should explore with them their willingness to have their care discussed with family members.

### Advance Care Planning and Clear Decision Making

*MRS R: The first decision was to absolutely follow his lead. I didn't know until we got to the hospital and he said, "Oh, I feel better here." He felt safer there. He had always said he wanted to die in his own bed. But that was not in terms of this illness.*

Advance care planning is an essential component of end-of-life care. It includes discussing preferences, values, and contingencies for end-of-life care, as well as preparing le-

gal advance directives, such as naming a health care proxy or executing a living will. Exploring patient wishes regarding after-death issues may be useful as well, including plans for autopsy, organ donation, funerals, and disposition of possessions. Although clear proof of the beneficial impact of advance directives themselves on costs, decision making, and clinical interventions has been elusive,<sup>56-58</sup> there is growing consensus that engaging in the process is important for patients, families, and clinicians.<sup>59,60</sup> Advance care planning is not a static document or a set of instructions, but rather is an ongoing process, and an opportunity to engage with patients and families. Even when advance care planning has begun early in a patient's illness, as it should, patient and family preferences may change, and it is critical for physicians to follow up and modify plans as the illness progresses.<sup>60</sup>

Patients develop treatment preferences, consider truth-telling, and undertake decision making within a cultural and ethnic heritage. In a study of 200 elderly people from 4 ethnic groups, 57% of Korean Americans and 45% of Mexican Americans believed that the family should be the primary decision maker, compared with 24% of African Americans and 20% of European Americans.<sup>61</sup> But even with the goal of honoring cultural background, patients and families must not be stereotyped because there is wide variation of beliefs within cultures, and personal characteristics may be as important as cultural influences. For physicians, cultural sensitivity is likely to be as important as cultural competence.<sup>62</sup>

For patients lacking decision-making capacity who have not previously identified a surrogate decision maker, it is generally appropriate to turn to the family.<sup>63</sup> Notably, though, predicting patient preferences is difficult for both family and clinicians. In one study, given only demographic and clinical information, clinicians were only slightly better than chance in predicting a patient's preferred code status.<sup>64</sup> In another study of actual patient-surrogate pairs using hypothetical scenarios, surrogates' predictions were accurate only 66% of the time.<sup>65</sup> Surrogate-patient agreement is often limited, even in cases in which patients and surrogates have discussed preferences beforehand.<sup>66,67</sup>

Even in the presence of an advance directive, family members may have conflicts of interest or disagree with one another. Strategies for achieving consensus among disagreeing family members include focusing on the known medical facts of the patient's conditions and continually refocusing on what is known about the patient's values and preferences.<sup>63</sup> Directing the family through the precept of substituted judgment, physicians can encourage each family member (both appointed surrogates and others) to imagine and discuss what the patient would want done for himself or herself—which is not always equivalent to what the family member would want done for the patient.<sup>49</sup>

Distant family and the unpredictability of physician and family schedules can combine to make decision making

## Box. Recommendations for Conducting a Family Meeting When the Patient Is Unable to Participate

### Prepare for the Meeting

Review medical issues and history.  
 Coordinate health care team.  
 Discuss goals of meeting with team.  
 Identify a meeting leader among the health care team.  
 Discuss which family members will be present.  
 Arrange a private, quiet location with seating for all.  
 Try to minimize distractions: set aside adequate time and seating, turn off pager if possible.

### Open the Meeting

Introduce all in attendance.  
 Review the medical situation.  
 Establish the overall goal of the meeting, by saying something like: “Today I’d like to make sure everyone understands how [the patient] is doing and answer all the questions that you have,” or “We wanted to meet today to discuss how [the patient] will be cared for at home.”  
 Be prepared for the goals of the meeting to change based on family’s desires.

### Elicit Family Understanding

Ask family members questions, such as “What have you been told about [the patient’s] condition?”  
 After hearing from the family, a helpful follow-up question is “Is there anything that isn’t clear that we can help to explain?”

### Elicit Patient and Family Values and Goals

Elicit goals of all those present, especially if multiple perspectives are held.  
 Begin with an open-ended question, such as, “Given what’s gone on, what are your hopes for [the patient]?” This may be followed by more specific suggestions for the family: “Sometimes getting home is an important goal for someone. Sometimes seeing a certain family member or friend is an important goal: are there things like this that you imagine are important for [the patient]?”  
 Understand ethnic and cultural influences on communication styles, family relationships, medical treatments, and end-of-life care by asking: “Can you please help me to understand what I need to know about [the patient’s] beliefs and practices to take the best care of [the patient]?”  
 Maintain focus on the patient’s perspective. Often this can help to relieve guilt that family members may feel over making decisions. Such questions could include “What do you imagine [the patient] would have done or wanted in this situation?” or “Our goal is not so much to think about what you would want or not want but to use your knowledge of [the patient] to understand what he or she would want in this situation.”

### Deal With Decisions That Need to Be Made

Achieve a common understanding of the issues.  
 Find out if the patient had made his or her wishes about the decision known by asking, “Had [the patient] ever discussed what he would want or not want in this kind of a situation?”  
 Reassure family members that they are making a decision about what is in the best interests of the patient, not necessarily what is in their own best interests.  
 Begin with open-ended assessments and then turn to specific interventions if necessary.  
 Offer clear recommendations based on patient and family goals, by suggesting, for example, “Given our understanding of the medical situation and what you’ve told us about [the patient’s] goals, I would recommend not pursuing dialysis.”  
 Seek consensus whenever possible, agreeing on the decision or on the need for more information.  
 Use summary statements, such as “It sounds like we are coming to an understanding that [the patient] would not want to continue on the ventilator. Is that how everyone understands his or her wishes?”  
 Consider the possibilities of seeing the decision as a “therapeutic trial” or as a health care team recommendation that requires only family assent.  
 Check for understanding of the decisions made, by saying something like, “I want to make sure everyone understands that we’ve decided to . . .”

### Close the Meeting

Offer a brief summary of what was discussed.  
 Ask for any final questions.  
 Offer a statement of appreciation and respect for the family: “I appreciate how difficult this must be, but I respect everyone for trying so hard to do right by [the patient],” or “I want to thank everyone for being here and for helping to make these difficult decisions.”  
 Make a clear follow-up plan, including plans for the next family meeting and how to contact the health care team.

### Follow up on the Meeting

Document the meeting in the chart.  
 Follow up with any information or reassessment agreed upon during the meeting, by saying, “When we last met, you were going to talk with your brother about our meeting. How did that go?”

even more difficult. In such cases, telephone communication and conference calls may be pursued. As with in-person meetings, having a clear goal for the call and a discussion leader are key. Although e-mail and Web-based systems may be easy methods for families to circulate updates, the inability to foster real-time, synchronous interaction generally limits their utility for family decision making. Families should be mindful that these modes of communication carry the potential for breaches in patient-physician confidentiality.

### Support for Home Care

MRS R: *The home caregiver doesn't know what they don't know. I didn't know questions to ask doctors. . . . I never talked to the doctor without my husband there. So, it was not always easy to ask a blunt question.*

MS L: *It was never presented to us what it would entail, in terms of taking care of him.*

MS P: *It's incredible what people at home can do and what they want to do just to keep people at home . . .*

Although family caregivers are important to the care of patients in the hospital<sup>49</sup> and nursing home,<sup>68</sup> the family caregiver role is a central element of home-based patient care. At home, the success of the care plan may depend on the physician's relationship with the patient's caregiving network. 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 department, with little preparation, training, or compensation.<sup>9</sup> A 1998 national survey of 1002 informal caregivers found that one fifth of all caregivers help with dressing changes and nearly 40% administer medications.<sup>6</sup> Among caregivers administering medications, half are responsible for managing 5 or more, and 1 in 6 caregivers must administer medications non-orally, including via injection. Mr R was taking 10 medications, all of them managed by Mrs R. A number of medications, such as lorazepam for anxiety and haloperidol for insomnia, were given as needed, creating an additional responsibility for Mrs R to make dosage and administration decisions. This became an overwhelming responsibility for her as Mr R's health declined.

Physicians' medication orders should provide the patient and caregiver with specific guidelines for their use and administration at home, especially for medications given by family caregivers on an as-needed basis. Evidence suggests that medications for breakthrough pain are underused in home care<sup>69</sup> and physicians, along with other members of the home care team, can help clarify the use of such treatments. Additionally, family caregivers require clear instructions about when and whom to call for help. Family caregivers require 24-hour-a-day access to professional advice. E-mail, online, handheld, and wireless communication technologies can supplement routine telephone access. Even for families who wish to continue to care for their loved one at

home,<sup>70</sup> caregivers require direction about which developments (such as sudden, massive, uncontrolled bleeding) might best be addressed by calling an emergency contact number (eg, 911) directly, and seeking care emergently in the emergency department or inpatient palliative care unit. Caregivers also should be instructed as to how to convey their loved one's wishes about advance directives when calling for emergency help.

Physicians are part of the interdisciplinary home care team that provides family caregivers with orientation, information, training, and support. Especially for patients not enrolled in hospice, physicians play a role in initiating and orchestrating, along with home health social workers and agencies, the multidisciplinary referrals and training family caregivers may require. Beyond their role as organizers and supervisors, physicians can make home visits and be reimbursed for this service.<sup>71</sup> Physician home visits have been shown to improve patient quality of life and delay nursing home admissions.<sup>72,73</sup> Additionally, the multiple roles physicians play in supporting home care create important opportunities for medical student and house staff education about palliative care and working within a clinical team.<sup>74,75</sup>

Physicians can help prepare family caregivers by orienting them to the expected natural history of the patient's condition, the care needs that might arise, and the options for the caregiver's response. Physicians should also educate families about their options when dying at home is not desired and describe the range of services provided by an institutional hospice or a hospital-based palliative care unit. Unfortunately, when Mr R's condition deteriorated to the point that he could no longer be cared for safely at home, the referral to the palliative care unit came from a concerned family friend, not from Mr R's physician, and the family members initiated admission on their own.

### Empathy for Family Emotions and Relationships

MS L: *[The burdens] just brought us closer. I felt very privileged to be able to be helpful to him and to be helpful to my mother. And it occasioned a lot of the most precious moments of connection that I'll always remember.*

MRS R: *Giving care at home made me feel useful. It only became scary for me at night when there were just 2 of us here, and I realized that if anything untoward occurred, I wouldn't be able to do anything for him.*

MS P: *The patient needs can be taken care of. There's more anguish for the family. I think it's harder on the family than it is on the patient.*

Family caregiving can both strengthen and strain personal well-being and family relationships. As in this case, adult children frequently assume responsibilities for ill parents and may have to adjust the expectations within their own nuclear families. Amid the challenge of integrating illness into family dynamics, family members may find themselves reacquainted with long-estranged relatives during the period of end-of-life care and bereavement.

Addressing family caregiver emotions and recognizing family dynamics may be a necessary prerequisite to optimum care of the patient. The personal characteristics and emotional strain of family caregivers may create barriers to placement of patients in appropriate care settings, leading family inappropriately to insist on or reject care in the intensive care unit, long-term care setting, home, or institutional hospice. Caregiver attitudes and burden directly impact the rate of patient hospitalization and institutionalization.<sup>76,77</sup> In a study of 40 caregivers of patients with mild to moderate dementia, caregiver depression negatively affected their assessment of the patient's quality of life,<sup>78</sup> which may bear on the caregiver's ability to serve as an appropriate surrogate decision maker.

Although family caregiving holds the promise of promoting patient autonomy and dignity, conditions such as diarrhea, hair loss, open wounds, and incontinence can sometimes lead to loss of privacy, embarrassment, or resentment for the patient. Preparing the family and patient for these contingencies, emotional troughs, and the inevitability of loss is critical.<sup>3,38,41,79</sup> Physicians can be helpful in recognizing and validating common feelings and reassuring family members about the quality of their care.<sup>3,38,46</sup> Empathic responses, such as saying, "This must be a very difficult time for you," communicate respect and support during an emotionally stressful, even traumatic, time. In a study of 988 terminally ill patients and 893 caregivers, caregivers of patients whose physician listened to the caregivers' needs and opinions had significantly less depression (27.6%) than caregivers of similar patients with nonempathic physicians (42.0%).<sup>7</sup> Adult day care, respite care, home care, social work services, and caregiver education and psychological support demonstrably improve caregiver satisfaction, quality of life, and burden.<sup>33,77,80-85</sup> Helping family caregivers identify support resources may be especially important for families of patients ineligible for the comprehensive services provided by hospice.<sup>79</sup>

### Attention to Grief and Bereavement

Grief worsens both physical and mental health, and it has been associated with increased depression, insomnia, substance abuse, suicidality, and mortality.<sup>86</sup> Research suggests that the caregiving experiences of family members influence their adjustment to the patient's eventual death.<sup>87</sup> Caregiving support may be even more important than grief support: a study of 73 adult family caregivers showed that caregiving support prior to the patient's death accounted for 29% of the variance in personal bereavement difficulties while bereavement support after the death accounted for only 2%.<sup>88</sup>

Bereaved family members highly value a physician condolence telephone call, letter, or visit, as well as attendance at the patient's funeral.<sup>89,90</sup> Such contact communicates caring, models appropriate coping with the loss, and allows physicians to answer family questions and assess for complicated grief. This communication may improve

bereavement outcomes.<sup>90</sup> Along with members of an interdisciplinary team, physicians can normalize the family member's feelings of grief and recommend basic but effective behavioral interventions such as daily activity, journal writing, time with empathetic friends, grief counseling, and support groups.<sup>91-94</sup> Around meaningful days, such as the deceased's birthday, yearly anniversary of death, and wedding anniversary, loved ones often experience a resurgence of intense grief and physicians may help by alerting the bereaved to this possibility. During the first year of grief and anytime thereafter, the diagnosis and treatment of major depression are vital.<sup>95</sup>

### CONCLUSION

The experience of caring for loved ones as they approach death can be one of deep fulfillment or significant trauma. In recognizing the burdens of family caregiving, communicating well, assisting with decision making, supporting home care, helping with caregiver emotions, and acknowledging bereavement, physicians have much to offer and much to gain. The appreciation and well-being of family caregivers may help sustain physicians. A physician's empathy and compassion may be more readily elicited in the company of those who love the patient and who have known the patient in both health and illness.

Nationally, education and compensation reform should enhance physician opportunities to be of service to family caregivers.<sup>38,96</sup> Legislation must improve and integrate family caregiver policy, so families do not have to needlessly duplicate effort. Dame Cicely Saunders wrote, "How people die remains in the memories of those who live on."<sup>97</sup> If dying is, at least in some measure, "what the family remembers,"<sup>51</sup> then physicians have a fundamental opportunity to support the profound experiences of family caregivers. In being of service to this legacy, physicians may foster healing and dignity at the close of life.<sup>98</sup> Improvements may come from the most basic of interventions. As Ms P concluded, *"I really think we need to listen more to what these people have to say. It's giving back a lot of control, but I think if we listened more, it would be a whole lot better."*

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**Other Resources:** For a list of relevant Web sites, see the *JAMA* Web site at <http://www.jama.com>.

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## ADDITIONAL CAREGIVER RESOURCES

### **American Association of Retired Persons (AARP) Caregiving Resources**

<http://www.aarp.org/inthemiddle>

### **Alzheimer's Disease Education and Referral Center**

<http://www.alzheimers.org/careguide.htm>

### **The Alzheimer's Store**

<http://www.alzstore.com>

“A Guide to Alzheimer's-Proofing Your Home”

### **The American Gerontological Society Online Caregiver Guide**

[http://www.healthinaging.org/public\\_education/eldercare/](http://www.healthinaging.org/public_education/eldercare/)

### **Caregiver Resource Directory**

[http://www.stoppain.org/caregivers/resource\\_form.html](http://www.stoppain.org/caregivers/resource_form.html)

Online service of Beth Israel Hospital, New York

### **Caregivers Marketplace**

<http://www.caregiversmarketplace.com>

### **Caregivers USA**

<http://www.caregivers-usa.org>

### **Caregivers in Action**

<http://communities.msn.com/caregiversinaction>

Family Caregiver Chat Hour, an online chat with others who serve as caregivers for their families. Tuesdays, 9:30 PM (Eastern time).

### **Center for Caregiver**

<http://www.caregiving101.org>

Offers caregivers basic, practical skills and strategies they need to care for their loved ones

### **Last Acts Family Committee**

<http://www.lastacts.org>

Consumer and family resources for end-of-life care

### **Local Red Cross Chapter Caregiving Classes**

<http://www.redcross.org>

### **National Alliance for Caregiving**

<http://www.caregiving.org>

### **National Council on Aging**

<http://www.ncoa.org>

<http://benefitscheckup04.governmentguide.com>

### **National Family Caregiver Assn**

<http://www.nfcacares.org>

### **Today's Caregiver Magazine**

<http://www.caregiver.com>

### **US Administration on Aging, National Family Caregiver Support Program**

<http://www.aoa.gov/prof/aoaprog/caregiver/carefam/carefam.asp>

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