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Caring for Patients Who Are Dying: The Hospice

Hospice care relies on the patient's family to provide day-to-day care. Most often, family members are committed and reliable caregivers; but when they are not, ethical problems loom. Take the case of Jeremy Benton. He is a seventy-year-old man with metastatic lung cancer who lives with his wife, adult stepson and grandchildren. Based on the disarray in the home, the loud arguing between husband and wife, and Mr. Benton's soiled clothing and bedding, the hospice assessment team worries that his wife, Lucy, is neglecting him.

Mrs. Benton, who drinks heavily, insists that she is taking good care of her husband. Once in a while, she acknowledges, she is too tired to clean him. "I get worn out from cleaning and changing him so sometimes I just let it go. And he eats what the rest of us get." Mr. Benton does not complain and in repeated conversations with concerned staff, he insists that he wants to die at home.

The hospice team, concerned as much about how he lives as how he dies, are convinced that Mr. Benton's care is woefully inadequate. Ribald sexual allusions, noisy arguments, and pungent odors are not ideal conditions in which to care for a patient who is dying, they believe. What can the team do as they reflect on the par-

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ticular understandings that seem to infuse the Benton household but challenge the team's idea of good hospice care?

Mr. Benton's insistence that he stay at home would appear to be a classic expression of patient autonomy. The team's concern represents their commitment to acting in the patient's best interests. Yet, best interests are multiple and shift according to the point of view adopted. Similarly, respecting autonomy does not require unmediated or "as is" acceptance of the patient's wishes.

Sometimes the only strategy for resolving such conflicts rests with the fine art of negotiation starting with mutual efforts to understand the situation from the other's perspective. In the home where the possibilities for changing ingrained behavior patterns are limited, and the decisions rendered are not for a single treatment or event, such explorations are essential.

In this situation, Mr. Benton cannot be autonomous without considerable assistance. The team

is essential if he is to stay home and receive comprehensive end-of-life care. Through negotiation and fact finding, the team can learn the meaning of "best interests" from his point of view. What are his goals at this moment in his life? Cleanliness and tranquility may be as alien to him as the odors and noise are to the team. For Mr. Benton, emotional and social ease are probably as important as his physical comfort; sadly, he might not be able to have both. If inquiry suggests that he is relatively untroubled with the situation, the hospice team can refocus their energies. They might try, once again, to work collaboratively and sympathetically with Mrs. Benton to determine the help she needs to care for her husband and to meet the team's minimal conditions for continued involvement in Mr. Benton's care. Regular monitoring and, if necessary, renegotiation may result in a solution that no one finds entirely satisfactory but one that all can accept. Often in difficult circumstances, that is the best we can hope for.

Death By Prescription: Pharmacy Ethics

In 1999 a *New York Times* article raised the prospect that pressure on pharmacists to increase prescription volume would erode their ability to counsel patients regarding dosage, side effects, and other safety concerns. Responding to the notion of "death by prescription," Daniel A. Hussar wrote an editorial in *Pharmacy Today* in which he acknowledged factors that could compromise the standing of pharmacology as one of the most trusted American professions.

Not unlike colleagues in medicine and nursing, during their more than 150 years of service American pharmacists have revised their ethical code to reflect transition from paternalism to a more collaborative relationship with patients and peers. The most recent revision of the Code of Ethics for Pharmacists, enacted by the American Pharmaceutical Association in 1994, describes the patient-pharmacist relationship as a covenant in which the pharmacist receives and maintains the trust of society by helping "individuals achieve optimum benefit from their medications . . . " This covenant relationship appears straightforward, even self-evident. But what should pharmacists do when patients do not want their assistance?

Consider for example the situation of a patient who says, "I am already late for work, and I need this medicine now. My internist prescribed it. That's good enough for me. Just print the instructions on the label so I can get going." The pharmacist has told the patient that the drug prescribed by his internist may have toxic effects if taken with a medication already prescribed by his orthopedist. (The harried patient forgot to mention this prescription when questioned by the internist.) Is it enough that the pharmacist has informed the patient of the possible risk, or should she insist on phoning the internist?

Years ago pharmacists' primary responsibility was fulfilled by accurately dispensing agents as prescribed by physicians. Today they have a greater duty to counsel and inform. Not only do pharmacists have special training and expertise in pharmacology, as this case shows they may have information about the patient's history unknown to prescribing physicians.

In this case ethics precedes etiquette. The inconvenience to this patient and others is outweighed by the responsibility to prevent potentially serious side effects.

e-Ethics provides discussion of important ethical issues in clinical care and organizational life. In specific cases, fuller ethical analysis may be required. The discussions in e-Ethics should not be construed as legal advice and do not necessarily represent official positions of Advocate Health Care.

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