

Writing community Rx to start improving the care of our dying



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GUEST ESSAYISTS

A year ago, one of our patients was in intractable pain. His prostate cancer had spread in spite of aggressive medical treatment. He chose to follow a path of aggressive palliative or comfort care. Choosing hospice has allowed him to live his life actively, with relief of his pain, while he brings closure to his life.

About that time, the Rochester Individual Practice Association and Blue-Cross BlueShield of the Rochester Area also made an important decision. Together we identified the delivery of quality end-of-life care as one of the most pressing health care issues facing our community. To assess how we are doing in this regard, we spent the last year surveying the community.

Hospitals, nursing homes, hospice programs, home care agencies, insurance company disease management programs, and skilled nursing facilities openly shared data that revealed both strengths and weaknesses in our system of care for the terminally ill. The greater than 50 percent response rate to our questionnaire demonstrates the concern that the leaders of our health care institutions have in improving quality of care at the end of life.

All of the responding institutions routinely ask patients at the start of care if they have an advance directive outlining the care they want to receive at the end of life and who should express their wishes if they are unable to speak for themselves. But our survey clearly shows that there is room for improvement.

Our major findings and recommendations focus on three areas for improvement:

■ **Advance care planning:** Too few people, especially those with chronic medical conditions like emphysema, heart failure, diabetes and cancer, have advance care directives. The result is that when these people become critically ill, their physicians and others will not know their wishes and how best to deliver their care.

Our recommendation is that every-

one have a comprehensive advance care directive. This includes a living will and the naming of a health care proxy to see that their wishes are carried out if they are unable to speak for themselves.

We are calling on the health care community to adopt a comprehensive advance care directive form that all area health care practitioners and institutions will honor. We are also encouraging health care and community organizations to develop educational programs showing the advantages of completing advance directives and discussing available options.

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■ **Pain and symptom management:** Pain must be more effectively managed. Patients should expect relief of pain and other distressing symptoms at the end of life.

Our recommendation is that practitioners and health care institutions establish comprehensive standards for assessing and treating pain at every site of care. The Joint Commission on the Accreditation of Health Organizations now requires that all hospitals record pain as a vital sign. That means pain will be regularly measured in 2001. Plans for responding to pain must be developed in the same way that a drop in blood pressure or a rise in temperature is addressed. We need to be sure that effective pain management is routinely available.

■ **Timely hospice referral:** Patients should be referred to hospice earlier. Our most surprising and disturbing finding was that 40 percent of people

die within seven days of admission to a hospice program. Earlier hospice referrals ensure that patients and families have the time to receive the benefits of physical, spiritual and emotional care provided by a team of caring health professionals.

Efforts are under way to improve training in end-of-life care for medical students, trainees and practitioners. The University of Rochester is developing a model curriculum for its students and residents.

On Thursday, there is a “Caring for Patients at the End of Life” symposium for area practitioners. Work is under way at Excelsus to offer a comprehensive program titled “Education for Physicians on End-of-Life Care” to area professionals this fall.

Even with these efforts, if we are to improve end-of-life care, we need our patients and their families to talk together, define their wishes for end-of-life care, complete advance care directives, and share them with their doctors. As we learned from survey comments, decisions made during a health care crisis are difficult, painful and unsatisfying. When the patient, family, proxy and staff are clear about the patient’s wishes and directions for care, the patient can receive the services he or she requested.

Recently, the Bill Moyers’ special on public TV, *On Our Own Terms*, helped raise public awareness of the advantages of advance care planning. We applaud the efforts of the local Coalition for End-of-Life Care to encourage families to talk openly about these issues and to educate the community about resources that can help when you learn a loved one is terminally ill.

The goal of the RIPA/Blue Cross Blue Shield initiative is to make Rochester a community of excellence in attending to people at the end of life. We welcome — and need — your support to accomplish these vital tasks. □

Beckman, medical director of the Rochester Individual Practice Association, chairs the Professional Advisory Committee on End-of-Life Care which conducted the community survey and now is working to see that its recommendations are carried out. Bomba is medical director for geriatrics the Excelsus Health Plans Inc., which includes BlueCross BlueShield of the Rochester Area. Copies of the RIPA/Blue Cross Blue Shield report are available by calling 242-0610.