

Leading the Way: Managed Care for Patients Near the End of Life

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In this issue of *The American Journal of Managed Care*, Dr. Ira Byock makes a bold claim. "Ultimately," he asserts, "it will be a marketing asset for a managed care organization to be known as a center of excellence in palliative care—and in some markets, it will be a necessity."¹

In 1997, my colleagues and I surveyed all managed care organizations (MCOs) offering managed Medicare to their over-65 population. Most plans had developed some form of education about advance directives. However, at that time (and despite some important exceptions), there was relatively little else focused on the physical, psychosocial, and spiritual needs of patients near the end of life or their families. What's more, during our follow-up telephone interviews with several MCOs, many interviewees seemed reluctant to focus on the topic. Some people were direct about their skepticism, saying in effect:

The end-of-life arena is a problem for managed care organizations. On the one hand, if we say we want to focus specifically on end-of-life concerns, we run the risk of further raising suspicions about managed care's motives. Our patients and the public might accuse us of simply wanting to save costs; we might be perceived as opportunists who want to avoid providing aggressive, expensive treatments to end-stage patients. On the other hand, if we get really good at providing palliative care, we might attract the sickest and frailest populations, thereby jeopardizing our financial solvency and our ability to serve all our patients.

Any national effort to improve care for patients near the end of life and for their families is going to have to take managed care's concerns seriously. How can managed care, now the primary source through which healthcare is delivered in the United States, feel safe enough to take on the enormously important challenge of providing better care to patients in the final stage of life? And can good end-of-life care,

as Dr. Byock anticipates, *really* be in managed care's own best interest?

With support from the Robert Wood Johnson Foundation, I had the privilege of chairing a national task force of leaders from disciplines and organizational backgrounds that had never before sat around the same table. The National Task Force on End-of-Life Care in Managed Care included medical directors of both nonprofit and for-profit MCOs; physicians and nurses with national expertise in palliative care; specialists in quality improvement, medical and nursing education, and healthcare financing; and ethicists with special interests in both end-of-life care ethics and organizational ethics. Our mission: to examine the ways in which managed care could take a leadership role in improving care for people near the end of life.

Many of the conclusions Dr. Byock draws in his article affirm key recommendations in our report.² While our recommendations were based on expert opinion and the survey and interviews we had conducted, Dr. Byock takes an analytical look across the demonstration projects funded over the last several years by the Robert Wood Johnson's National Program in Excellence in End-of-Life Care. As director of that program, he draws lessons from the collective experience of its projects, some of which took place within managed care settings.

His insights, although in need of confirmation through future empirical work, are powerful. For example, a vexing problem within the field is determining when to initiate palliative care and identifying exactly which patients should receive this care. In other words, given prognostic uncertainty, how

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should healthcare professionals define the patient population they wish to serve? The demonstration projects invented ways to answer that question—answers that provide models for how others might do so as well. Furthermore, programs that performed best paid careful attention to advance care planning and established individualized care management strategies to ensure care coordination, as patients moved between settings and among providers. Dr. Byock points out that managed care is ideally suited for coordinating care, which has been a major weakness of the fee-for-service model.

Perhaps his most powerful insight, though, is that ownership of the financial risk of caring for these patients may correlate with higher quality of services. Innovation seems to have thrived most successfully in settings that on the surface appear very different, eg, Veterans' Administration hospitals, prisons, a state department of mental health, and an urban health system serving a dually eligible pool of indigent patients. Beyond their commitment to improving end-of-life care, what did these very different settings have in common?

Dr. Byock observes that each one had full responsibility for all the financial risk associated with a given patient population. Cost shifting was not possible, and incentives were therefore aligned to encourage more careful advance care planning and care coordination.

If the MCO is both the insurance underwriter and the party at financial risk, then Dr. Byock's observation may prove true. However, if recent trends continue, with more physician groups assuming the risk and MCOs supplying only administrative services, an essential advantage of managed care may be attenuated. The key will be maintaining structures that discourage cost shifting.

If cost shifting can be avoided and if MCOs are willing to attract and retain chronically ill patients, it may well be that managed care models of care delivery and financing can at last untie the Gordian knot of suboptimal palliative care, which has plagued the American healthcare system. Indeed, the National Task Force on End-of-Life Care in Managed Care found that managed care was ideally suited to meet this challenge, because it has special tools and strategies not available under fee-for-service arrangements. Managed care organizations can and do:

- Institute systems of accountability
- Conduct population-based health studies
- Disseminate clinical guidelines
- Educate clinicians and patients

- Motivate improvements in clinical practice through performance measurement
- Monitor outlier practices
- Provide incentives to reduce inappropriate variations in practice patterns, and
- Develop interdisciplinary, team approaches to care.

All these strategies are powerful points of leverage. Imagine if they were brought to bear on behalf of end-of-life care.

While MCOs of various types have the tools and structures to help, will these organizations move into the palliative care arena with confidence, given their concerns about the public's trust? And, even if that trust could be nurtured, will managed care plans be able to withstand the potential financial implications of becoming centers of excellence in palliative care?

Regarding the first question about potential public image concerns, it is my view that in 2001, this problem should at last become a non-problem. I hold this view not because we are in a more managed care-friendly environment, but because the end-of-life field itself has moved on.

In its first 2 decades (mid-1970s to roughly the mid-1990s), most end-of-life policy makers and researchers saw the problem as one of coming to societal agreement on when it was ethically and legally permissible to stop unwanted, burdensome treatments. The national debate began with the case of Karen Ann Quinlan, a young woman in a persistent vegetative state, whose parents wanted her removed from a ventilator. The hospital and physicians worried: would this be killing? They insisted that the parents seek a legal opinion, ultimately rendered by the famous decision of the New Jersey Supreme Court. Hundreds of other so-called right-to-die cases soon followed throughout the late 1970s and through the early 1990s. Cumulatively, these cases achieved a broad national consensus: in the United States, competent patients and the families of incapacitated patients have the right to refuse life supports, if the likely burdens of continuing support seem, from what is known about the patient's values, to outweigh the likely benefits.

As legal support for termination of treatment grew, end-of-life reformers began promoting the use of advance directives, such as living wills and durable powers of attorney for healthcare, as a means of effectuating these newly defined rights. Thus, throughout the 1980s and early 1990s, the end-of-life care field was focused predominantly on trying to ensure that the healthcare system would

know what patients themselves wanted, so when patients perceived life supports to be highly burdensome and nonbeneficial, the measures could be withheld or withdrawn. The assumption was that this kind of knowledge of patient preferences would ensure better quality care for those patients who were suffering from high technology deaths.

Then came the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) and with it a sea change in thinking. Participating physicians received 2 reports on their patients—one describing their patients' views regarding frequency and severity of pain, desires for cardiopulmonary resuscitation, and related end-of-life measures, and another with prognostic data, including the likelihood of surviving to 6 months and of being severely impaired 2 months posthospitalization. The researchers believed that physicians armed with such detailed information about patient preferences and prognostic data would make better care decisions and reduce inappropriate health resource utilization. Nevertheless, despite exhaustive efforts, the SUPPORT intervention had no effect on key outcomes, such as timing of do-not-resuscitate orders or frequency and intensity of pain.³ Its failure was a clarion call for reform.

Today in the United States, we have certainly not abandoned our emphasis on patients' rights. We still recognize that end-of-life care involves many hard decisions about when to pursue or forgo life-sustaining treatments. Because of SUPPORT's failure, however, most professionals in the field now conceptualize the problem in a much broader way.

The earlier focus was primarily on deciding when to stop treatments and on figuring out who should get to decide this. In other words, the focus was disproportionately on what healthcare professionals should *not* do. Today, in the field of palliative care, the focus is much more clearly on what healthcare professionals *should* do. It is on delivering excellent clinical services to patients near the end of life and to their families. Rather than stirring up patient and

family mistrust, MCOs that achieve excellence in managing pain and other distressing symptoms, coordinating services, supporting patient's emotional needs near the end of life, and helping relatives come to terms with their grief are likely to win many kudos from grateful families. Plans that measure how well they are doing and publicly disclose their outcomes will win even higher approval ratings.

But what about the second question? Even if the public wants good end-of-life care and trusts managed care to deliver it, will getting good at palliative care lead to plan insolvency? Thanks to the Robert Wood Johnson Foundation-funded projects ongoing around the country (see online journal *Innovations in End-of-Life Care* at www.edc.org/lastacts for examples), we have growing evidence that excellent end-of-life programs need not break the bank. Indeed, cost efficiencies may even occur, although it is too soon to know for sure or to quantify the amount of potential savings.

One thing does seem certain. As more and more demonstration projects proliferate, the word will get out. Moreover, the growing demand for outcome measurement and public reporting will fuel additional public expectations.⁴ Ultimately, Dr. Byock's prediction may well come true. Managed care organizations may have no choice but to lead the way.

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