Experts Press for Greater Focus On Care Along With Cure

This is the first in a series of articles focusing on developments in palliative and supportive care.

Most oncologists view palliative care as the treatment of last resort, called on when "nothing more can be done" for a patient. But many experts believe that the philosophical and institutional walls that confine palliative care to dying patients and restrict the scope of its interventions deny effective symptom relief to both terminally ill cancer patients and those in earlier stages of disease.

The conventional assumption that "only when the curing effort is over does caring start" is offensive, not least because it implies that those who try to cure do not also care, said Sam Ahmedzai, M.D., professor of palliative medicine at the University of Sheffield, U.K., and associate director of the Trent Palliative Care Center.

Harmful Thinking

But this type of thinking, Ahmedzai believes, is also harmful. It not only hampers effective symptom management for patients not identified as terminally ill, but also denies those who are in late stages of disease the benefit of certain interventions because they are considered too invasive, too costly, or otherwise inappropriate for the palliative setting.

The word "palliation" derives from the Latin pallium, or cloak: Instead of vanquishing disease, the palliative approach cloaks or disguises it by treating the symptoms. (The term "palliative care" normally refers to symptomatic treatment of patients whose underlying disease is no longer being actively treated; the more inclusive term "supportive care" refers to interventions directed at the patient’s physical and psychological comfort, whatever the prognosis.)

Inevitably, the palliative care field lacks the glamour inherent in the pursuit of a cure for cancer. Everyone wants a cure and, as a result, the lion’s share of resources and publicity is directed to that end.

Nevertheless, nearly half of all patients are still incurable, meaning that palliative treatment may ultimately benefit them most. Given these facts, some health care experts believe the hospice philosophy, emphasizing comfort and dignity in dying, needs wider implementation. In addition, they said, new drugs and other technologies can ease the suffering not only of dying patients but of all cancer patients, starting at the time of diagnosis.

"The majority of physicians believe there’s a curative intervention at every step in the disease process — there’s always ‘one more chemotherapy,’” said Paul Coluzzi, M.D., regional medical director of Vitas Healthcare Corp., Orange, Calif.

"Generally, the only way we know how to instill hope in patients is to give them an active medical intervention. In contrast, the palliative universe never cures anyone, and if cure is what you’re hoping for at all times, you can see how palliative care is going to get the short end of the deal.”

Curative Orientation

The hospice movement, which in the mid-1960s spread across Britain, and later to the United States, was a major force in promoting palliative care. Hospices were created to serve the needs of terminally ill patients, which were seen as hopelessly at odds with the aggressively curative orientation of the medical establishment.

Added impetus came from the publication in 1988 of the World Health Organization’s treatise on pain relief and palliative care. But palliative and supportive care are still far from optimally integrated into the cancer care system.

Hospice care, which addresses the unique physical, psychological, and spiritual needs of the dying, can be provided not only in hospice facilities, but also wherever patients are, whether in their own homes or in nursing homes. In fact, Coluzzi said, the vast majority of hospice care in the United States is given outside conventional hospices.

Nevertheless, he said, only one-third of terminal cancer patients get hospice care.

In the March 1995 Journal of Clinical Oncology, Coluzzi and colleagues published a survey of supportive care services at National Cancer Institute-designated cancer centers. Sixty-one
percent of the centers reported research programs in supportive care. Most centers provided some specialized services such as pain management. But the authors concluded that these services have developed in a fragmented manner, and that oncologists are infrequently involved.

In addition, the authors wrote, “it is surprising that only 56% of cancer centers offer Medicare- or non-Medicare-certified hospices. There is no indication that these institutions offer or refer to other hospice programs. This suggests that the true integration of palliative care and terminal services in cancer care is inadequate.”

A new federal law that went into effect in 1995 requires that discharge planners inform all terminally ill patients about hospice services.

Coluzzi acknowledged that his own decision to move from a cancer center to his position with a hospice organization was partly due to his frustration at being unable to provide comprehensive supportive care services within the cancer center.

Poorly Controlled

In Britain, where the Royal College of Physicians recognizes palliative medicine as a subspecialty, awareness is probably higher than in the United States. But even in that country, a recent review of palliative care standards found that symptoms were often poorly controlled, teamwork was underdeveloped, and existing palliative care services were underused.

Coluzzi said the alienation of palliative care from disease-oriented medicine is also a problem in the United States. “You need to integrate comfort right up front,” he said. “For example, for someone who’s going to be cured of their illness with a bone marrow transplant, without good palliative strategies [life] is going to be a living hell for 6 months.”

Technological advances have improved the potential for palliative care, Ahmedzai said, but many physicians maintain the attitude that “these patients are too far gone for high-tech interven-

Stat Bite
Cervical Cancer Screening by Age, 1987 and 1992

In National Health Interview Surveys, the overall percentage of U.S. women who reported having a Pap test in the past 3 years remained stable from 1987 to 1992. Particularly for older women, cervical cancer screening rates fall substantially short of the national health objective for the year 2000. Lack of health insurance, lack of a primary care physician, and poor communication between women and their physicians each likely contribute to the discrepancy.

Women Reporting Pap Test Within Past 36 Months, %*

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<th>Age, y</th>
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<th>30-39</th>
<th>40-49</th>
<th>50-59</th>
<th>60-69</th>
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<td>73</td>
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<td>67</td>
<td>64</td>
<td>57</td>
<td>59</td>
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*Excludes women who have had a hysterectomy.

Source: MMWR Morb Mortal Wkly Rep, 1996;45:57-61 — By Nancy Breen, Ph.D.
tions” such as endobronchial prostheses to assist breathing. “These have been used for years in the acute setting, but only recently in palliative care. It’s an uphill battle to convince people that it’s an appropriate use of the technology.”

Ironically, he added, the hospice movement in Britain has in some ways become an obstacle to progress in palliative care. The movement was founded as a holistic alternative to the increasing depersonalization and technology-worship of the medical establishment, he added.

But some of the leaders of what has now become the hospice establishment, Ahmedzai said, retain such a resistance to technology that they have erected their own wall around the concept of hospice, excluding the possibility that emerging technologies may actually help ease the suffering of terminally ill patients without being unduly invasive.

Escaping the System

Hospice philosophy holds that “patients come to hospice to escape from the medical system,” he said. “Whereas I think most patients want the best of both worlds. We should be getting over that dichotomy by now.”

In the United States, where the hospice system is less well-established than in Britain, and where technology is even more pre-eminent, this is probably the least of the problems facing palliative care. Coluzzi said his company “will pretty much offer whatever intervention needs to be done to promote the comfort of the patient,” but added that “in fact at that stage of life, for most interventions the burden is greater than the benefit.” Both he and Ahmedzai stressed the need for well-conducted research into the effectiveness as well as cost-effectiveness of palliative measures.

“One of our aims is to achieve the same degree of sophistication in trials of palliative care” as is standard in trials of curative or life-prolonging treatments, Ahmedzai said.

Experts agreed that a major problem is the lack of palliative care training in medical education, particularly in pain control where formal training opportunities are scarce.

“My experience is that doctors in the community learned about pain management from hospice, not in school or by reading a journal,” Coluzzi said. “In the past year the Journal of Clinical Oncology has only published three articles on the issues of pain and palliative care,” he added as an aside. “That’s another indicator that these issues are not in the consciousness of most medical oncologists.”

Claudette Varricchio, Ph.D., of NCI’s Community Oncology and Rehabilitation Branch, said that “pain is an area that does not get particularly well-addressed in medical school education, in residencies and fellowships. Somehow or other, they’re supposed to absorb it out of the air, I guess! In the last 3 years or so,” she added, “there’s been much more attention focused on the area, with the [federal Agency for Health Care Policy and Research] guidelines on both cancer pain and acute pain management, along with the grass-roots movement of the state cancer pain initiatives. The main problem has been that, although we know a lot about pain and how to manage it, somehow it doesn’t filter down to affect how patients are actually managed.”

New Programs

In response to concerns raised by palliative care advocates, NCI in 1994 invited grant applications to create new educational programs in palliative care, which the institute acknowledged as a “neglected area.” Eight such programs are now being developed at medical schools across the country.

Ahmedzai believes the creation of a palliative care specialty in Britain was a step in the right direction, because the move acknowledges that palliative care is a discipline requiring special skills, and will require at least some physicians to learn those skills through formal training.

“When it was established as a specialty, there was a deep schism between those who thought it was a legitimate specialty and those who didn’t,” he recalled. “Many general practitioners will say palliative care is meant to be part of their role. But it would be difficult for a general oncologist to really keep up to date on the whole range of palliative care techniques.”

While there seem to be no plans to create a specialty in the United States, Coluzzi said U.S. physicians who specialize in hospice and palliative care generally keep up and keep in touch through such organizations as the Academy of Hospice Physicians.

— Tom Reynolds