



CHAPTER 3. Palliation

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PALLIATION

DEFINING PALLIATION IN NEW JERSEY

The initial challenge facing the Palliation Workgroup under the first edition of the *Plan* was to develop a definition of palliative care that was operational, yet inclusive of a variety of perspectives. Workgroup members noted a lack of consensus in the healthcare world on the meaning of the term *palliative* care. One widely accepted definition—an early definition developed by the World Health Organization (WHO)—begins, “Palliative care is the active total care of patients whose disease is not responsive to curative treatment ...” A major drawback with this definition, in the workgroup’s view, was the limitation of access to palliative care to those at the end of life, when others with chronic rather than terminal illness may also benefit. Subsequently, in 1990, WHO suggested a more global approach by stating, “... control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment.”¹ It is this latter, broader definition that the Palliation Workgroup chose as a model for its own definition.

Another issue considered by the workgroup was the relationship of palliative care to hospice care and a tendency among professionals in the two fields to view their efforts as mutually exclusive. The impact of reimbursement issues on palliative care was a third issue considered. Other challenges in palliative care arise from cultural, ethnic, racial, and religious differences. In developing a definition that was sufficiently inclusive professionally that the interdisciplinary approach would not become lost in the more familiar medical model hierarchy, workgroup members strove to be sensitive to these issues and to the resultant political implications.

Acknowledging that those with cancer are increasingly *living with it* rather than (quickly) *dying from it*, the workgroup concurred that palliative care was certainly indicated for patients whose cancers were responsive to curative treatment, as well as for those in need of end-of-life care. For patients with cancer at any stage, the benefits of care that recognizes psychological distress and spiritual needs as well as physical symptoms are readily apparent. In recognition of these deliberations, the workgroup proposes the current 2006 definition, slightly revised from the 2001 definition that appeared in the first edition of the *Plan*.

“Palliative care is a coordinated, interdisciplinary approach to healthcare that enhances the quality of life of people with cancer and other illnesses. It targets the physical and psychological symptoms and spiritual needs of survivors from the time of diagnosis to end-of-life care in all settings.”

(Palliation Workgroup, 2006)

Note that through the phrase “from time of diagnosis to end-of-life care in all settings” workgroup members intend to include those with both chronic and terminal illness as appropriate recipients of palliative care.



IMPORTANCE OF PALLIATION IN CANCER CARE

Palliation is frequently described as managing the physical, emotional, and spiritual needs of both patient and family. This comprehensive approach requires a multi-disciplinary team for care, including nursing, pharmacy, social work, volunteer services, pastoral care, nutrition, arts, physical therapy, and medicine.^{2,3}

The first hospice opened in New Haven, Connecticut, in 1974, inaugurating the hospice movement in the United States. The mission of a hospice was to allow patients to live as long as possible and then to die with the basic elements of a good death: care, communication, continuity, control, calmness, and closure.² Although it evolved out of hospice, palliative care has grown to encompass all stages along the continuum of care, including improving and maintaining a patient's comfort, dignity, and quality of life, whether in an inpatient or outpatient setting. (See Chapter 5 Childhood Cancer for additional information about palliation.)

Cancer patients are increasingly seeking complementary and alternative medicine (CAM) to aid in disease- and treatment-related symptom management. CAM includes alternative medical systems, mind-body interventions, biological-based therapies, manipulative and body-based methods, and energy therapies.⁴ Both patients and physicians must be aware of the risks and benefits associated with CAM use in palliative care.

Although it evolved out of hospice, palliative care is quickly becoming a more common practice in mainstream U.S. healthcare⁵ and is a key issue in cancer control. The potential number of cancer patients needing palliative care services in New Jersey is very high. As noted earlier in this *Plan*, the American Cancer Society estimates that 43,370 new cancer cases will be identified and 17,140 cancer deaths will occur in New Jersey in 2007.⁶

However, despite advances in palliative care in the past three decades, many cancer patients continue to suffer from unmanageable symptoms, including an unacceptable 70% to 90% experiencing acute pain.⁷ While approximately one-half of all terminal cancer patients receive hospice care at the end of life, most could benefit from comprehensive palliative care earlier in the disease continuum.⁸ Cancer patients receiving palliative care reported prevalence of lack of energy, pain, dry mouth, shortness of breath, and difficulty sleeping.⁹ Pain includes physical and mental as well as spiritual manifestations (feelings of abandonment, anger, betrayal, despair, fear, guilt, sense of meaninglessness, regret, self-pity, and sorrow/remorse).² Barriers to seeking effective pain management include a patient's reluctance to report pain, fear that pain signifies advancing disease, and the desire to be a "good" patient and not bother the physician with complaints of pain.²

Every year the number of New Jersey residents who die with cancer in an inpatient setting is decreasing. In 1989, approximately 63% of New Jerseyans who died from cancer were inpatients, compared to 42% in 1998.¹⁰ As an increasing number of people are living with and dying of cancer in their homes rather than in medical facilities, so too expands the need to provide quality, comprehensive, and multi-disciplinary outpatient palliative care throughout the continuum of disease.

However, the cost of palliative care is also increasing. Medicare hospice expenditures climbed from \$205 million in FY1989 to \$2.1 billion in FY1998.¹¹ Medicaid hospice expenditures rose from \$1.5 million in FY1987 to \$197.2 million in FY1999. New Jersey was the 35th state to offer hospice under Medicaid in 1992.¹¹ Expenditures for palliative care will continue to rise due to an aging population,



increasing interest and concern about palliative care and end-of-life issues in conjunction with rising healthcare costs. Yet research shows that palliative care programs can also lower “costs per day” during a hospital stay. Factors contributing to lower costs per day include transfers out of the ICU and reduction in ancillary services and pharmacy costs.¹²

In the next decade, barriers to effective palliative care at all levels must be overcome. The Palliation Workgroup determined that addressing lack of awareness among healthcare professionals and the public about palliative care is a priority in New Jersey. Secondly, access to palliative care must be increased. Both these issues are described in further detail in the remainder of this chapter, and recommendations for improvement are outlined.



GOALS, OBJECTIVES, AND STRATEGIES

The recommendations of the Palliation Workgroup are summarized below for the following focal areas:

- Education
- Access
- Complementary and alternative medicine

OVERALL GOAL To increase awareness of and access to palliative care.

EDUCATION ON PALLIATIVE CARE

In order to influence quality of life in a positive manner, there must be clarity regarding the goals of care. To achieve clarity, the clinician must be knowledgeable about options that exist in the domain of palliative care along with the primary therapies. Just as important, the patient must also be aware of available options.

The challenges facing patients and their families at the time of diagnosis, during treatment stages, and continuing into survivorship years, are significant not only physically, but also psychosocially and spiritually. Therefore, effective, responsible care requires the integration of counseling into the treatment plan, whereas medical professionals may not regard this as a core component of care. Another problem impeding broader access to palliative care is the fact that patients and their surrogates may not be aware of the care options that exist.¹³

Despite the many societal and professional barriers to effective pain management, the Palliation Workgroup has identified addressing physician knowledge gaps, as well as misconceptions about pain management and symptom control, as the top priority to improve palliative care in New Jersey. In recent years, several medical and nursing programs have added education regarding palliative care concepts to their curricula. Many require that a hospice rotation be included in the clinical experience, since the focus of hospice is on pure palliative care. Palliative care should also be integrated into continuing professional education. The number of professionals certified in palliative care may be expected to increase, as educational opportunities in the field become available.

Although small steps have been made toward improving healthcare professionals' understanding of palliative care, the need for better care that promotes quality of life continues to grow. However, the transition from a medical model of care to a holistic one requires a paradigm shift in healthcare philosophy. Healthcare professionals and the public need support in understanding dying not as a failure of medicine, but as a natural part of life. People are living longer with chronic illnesses, and many are dying more slowly. Healthcare professionals need to respond to the challenge of supporting quality of life in addition to length of life.

Education is the first step in understanding suffering. With knowledge comes the power to truly affect quality of life along the entire continuum of care and, most intensively and poignantly, at the end of life. Therefore, the Palliation Workgroup proposes the following educational goal, objective, and strategies as next steps in improving palliative care in New Jersey through provider education.



GOAL PA-1

To integrate knowledge of palliative care into professional, public health, and legislative systems.

Objective PA-1.1

To educate and mobilize legislators, healthcare professionals, and the general public regarding the right to access palliative care and the benefits of comprehensive palliative care in all settings.

Strategies

- PA-1.1.1** Integrate training on palliative care into primary and continuing education for practicing professionals.
- PA-1.1.2** Develop a public education plan on palliative care for targeted populations based on capacity and needs assessments.

ACCESS TO PALLIATIVE CARE

Members of the Palliation Workgroup hold that every patient in New Jersey is entitled to access to palliative care services, regardless of the chronic illness from which they are suffering and regardless of the setting in which they may be found—whether in their own homes; a long-term care facility (such as nursing home, mental institution, center for the mentally and physically challenged); a hospital; an assisted-living facility; a boarding home; a state veterans’ hospital; or a prison. Many of these patients will have family members and/or significant others (hereafter referred to as the family) who are entitled to the supportive care services offered by palliative care.

Due to conflicting regulations, especially within institutional settings, patients may have difficulty receiving appropriate palliative care services, even when the patient and family desire such services. Healthcare providers, as well, often become frustrated with the system, as they cannot provide appropriate care for the patient and family. On the other hand, even when the focus on curative care is no longer the avenue of choice, some healthcare providers may find it difficult to offer palliative care. Other times, the distinction between curative and palliative care may not be clear-cut, necessitating the addressing of a patient’s needs on an individual basis.

While Medicare and a number of insurance and managed care plans cover hospice, palliative care services are often covered only indirectly under another aspect of care, if at all. In reality, palliative care services and hospice should be part of a continuum of care, in which patients and families can make choices they are comfortable making and ready to make, with support and guidance from healthcare professionals. Patients and families need to be empowered to participate in healthcare decisions.

Further dialogue needs to take place with insurance companies and managed care plans as to the benefits of palliative care services for those in need and the long-term savings to payment sources. Government



agencies and institutions also need to be educated as to the importance of palliative care, the long-term savings, and their obligations for reasonable reimbursement and/or provision of these services.

In addition to institutional and financial barriers to access, numerous patient and family barriers have been identified.¹⁴ Socioeconomic backgrounds, cultural backgrounds and practices, personal values and beliefs, and religious or spiritual belief systems can influence perception of palliative care services.¹⁵ For widespread acceptance of palliative care to occur, a multi-pronged effort is needed to engage healthcare providers, voluntary community-based organizations, faith-based groups, and other identified entities that are in a position not only to stimulate establishment of palliative care in healthcare settings in their communities,⁵ but also to provide information to and support for patients, their families, and the community at large.

There are also legal barriers to providing quality end-of-life care. One example among several relates to adequate pain management. Many effective pain management drugs have been classified by the U.S. Drug Enforcement Agency (DEA) as Schedule II controlled substances and are therefore subject to state and federal regulations. Patients and their families are often hesitant to take these controlled substances, while physicians may be fearful of prescribing them due to intense legal scrutiny. Legislators can help to remove these barriers, which would benefit every constituent in their districts.^{16,17}

Research has been done on cost savings and quality-of-life outcomes for patients and families that need and receive palliative care services. Comfort from pain, relief of symptoms, emotional and spiritual supports are only a few of the benefits for patients. For example, it is important to recognize pain as the fifth vital sign, along with blood pressure, temperature, pulse, and respiration. Prevention and/or reduction of physical, emotional, and financial problems, as well as prevention of long-term psychosocial problems, are but a few of the benefits for families. Social workers and pastoral counselors within healthcare settings can be helpful in obtaining resources to assist patients and families in obtaining needed palliative care services.

Existing data have been compiled for this *Plan*. Future surveys or research projects can focus on gaps in the existing data. Foundations, grants, insurance companies, government agencies, universities, and healthcare centers may be avenues for future funding. Commissions or task forces, such as that charged with producing this *Plan*, may be another avenue of study and recommendations for appropriate funding.



GOAL PA-2 To ensure that palliative care services are accessible to cancer patients and others with chronic illnesses.

Objective PA-2.1

To ensure reimbursement for palliative care services.

Strategy

PA-2.1.1 Investigate palliative care reimbursement initiatives and engage insurance companies in further discussion of reimbursement for palliative care services, including psychosocial and bereavement counseling for the patient and the patient's family.

Objective PA-2.2

To develop standards for palliative care.

Strategy

PA-2.2.1 Link with national organizations that can help frame the palliative care issue on a national scale.

Objective PA-2.3

To identify, prioritize, and reduce the system barriers to palliative care service availability.

Strategies

PA-2.3.1 Develop strategies to address the gaps in palliative care services.

PA-2.3.2 Educate state legislators who can serve as advocates in supporting palliative care policies.



Objective PA-2.4

To identify, prioritize, and reduce personal barriers to palliative care services.

Strategy

PA-2.4.1 Partner with interdisciplinary and grassroots organizations to alleviate personal barriers to palliative care.

COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) IN PALLIATIVE CARE

Complementary and alternative medicine cannot be overlooked by conventional medicine. CAM is being used by a significant proportion of the U.S. population for therapy as well as for health promotion and disease prevention. CAM has become increasingly prevalent over the past few decades among cancer patients in particular, who often experience pain, anxiety, and fatigue as a result of their disease and treatment.⁴ An estimated 94% of cancer patients experience disease-related symptoms that are not addressed by conventional medicine.¹⁸

The National Center for Complementary and Alternative Medicine (NCCAM) defines CAM as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.”¹⁹ Complementary medicine is generally used in conjunction with conventional medicine, while alternative therapies are used in place of the conventional.¹⁹ However, the delineation between conventional medicine and CAM is becoming increasingly blurred as some forms of CAM are now taught in medical and nursing schools, and hospitals and health maintenance organizations now offer it.²⁰ In fact, laws in some states require that health plans cover it.²¹ CAM is identified with the following types of therapies: acupuncture, biofeedback, chiropractic, commercial weight-loss programs, energy healing (including magnets), folk remedies, music therapy, herbal medicine (including teas), homeopathy, hypnosis, imagery, lifestyle diets (e.g., macrobiotics), massage, mega-vitamins, relaxation techniques (including meditation), self-help groups, and spiritual healing.^{4,18,19} It is estimated that as many as 84% of cancer patients in the U.S. have utilized CAM for its potential to boost their immune systems, relieve pain, and control the side-effects of disease and treatment.^{4,18}

The funds expended for CAM have also increased and are significant. The estimated expenditures for alternative medicine professional services in the U.S. increased over 45% between 1990 and 1997 and were conservatively estimated at \$21.2 billion in 1997, with at least \$12.2 billion paid out of pocket. Total 1997 out-of-pocket expenditures relating to alternative therapies were conservatively estimated at \$27 billion, which is comparable with the projected 1997 out-of-pocket expenditures for all U.S. physician services. Further, this increase was attributable primarily to an increase in the proportion of the population seeking alternative therapies, rather than increased number of visits per patient.¹⁸

The reasons people with cancer choose CAM are multiple. Many cancer patients are likely to do so when conventional therapies no longer offer the possibility of cure or remission. Others seek CAM out



of fear of chemotherapy, surgery, and radiation, the most common conventional therapies. For some tumor systems, no conventional therapy exists or there are only experimental clinical trials whose outcome is unknown. It has been suggested that cancer patients may feel a loss of control that leads them to use CAM as a way to regain or exercise some control over their care; through CAM they achieve a sense of contributing to the care of their malignancy.^{18,22-24}

Studies have shown that those using CAM tend to have a higher education level, higher income, and hold a philosophical orientation toward health that can generally be characterized as holistic, e.g., they believe in the importance of body, mind, and spirit in health.^{18,23} Users of alternative healthcare are also more likely to report poorer health status than nonusers. However, users of CAM are reported to be no more dissatisfied with or distrustful of conventional care than nonusers.²³

While the benefits of CAM are becoming increasingly accepted, the use of such non-traditional therapies can be detrimental to the cancer patient's health. In a study of CAM users, close to 90% of respondents who saw a provider of unconventional therapy did so without the recommendation of their medical doctor. More than 70% of CAM users did not inform their medical doctor of this use.^{25,26}

This lack of disclosure can have serious consequences for cancer patients and others. Because vitamins and herbs are considered to be nutritional supplements, they are unregulated by the U.S. Food and Drug Administration (FDA). This permits a lack of quality control in the products, and misleading labeling can persuade patients they are taking an appropriate amount, when in fact they are receiving excessive amounts of potent or harmful substances.²⁴ Additionally, CAM may interact with commonly prescribed drugs and other conventional therapies in unpredictable and potentially adverse ways.^{18,23,27} Patients should discuss with their physician any use of CAM before, during, or after treatment.

It is because CAM, for the most part, lacks scientific evidence for safety and efficacy, as required by the FDA for the approval of drugs and by peer-reviewed medical journals for the publication of research reports, that medical authorities set it apart.²⁸ Although most CAM therapies are relatively low risk, any therapy that results in a delay of a proven therapy indirectly causes harm. Particularly troublesome to conventional providers are the alternative therapies that espouse a simple etiology to explain all cancers. It is generally agreed that there is inconclusive evidence about the safety, efficacy, mechanism of action, and cost-effectiveness of individual alternative treatments.^{23,27} Exceptions to this premise include the use of spinal manipulation for acute low-back pain, acupuncture for nausea, and behavioral and relaxation techniques for chronic pain and insomnia.²⁹⁻³¹

It is expected that as the public's interest in CAM increases, the number of conventional schools offering courses in CAM will continue to grow. Centers in medical schools and schools of public health to study CAM have also been established. The Office of Alternative Medicine, renamed the National Center for Complementary and Alternative Medicine, under the auspices of the National Institutes of Health, was established in 1992. This Center is making headway in funding studies that evaluate unproven treatments for cancer.

The public is increasingly exposed to information about CAM and conventional treatments through direct-to-consumer (DTC) advertising in the media and on the web. Although the reliability of the public information received through these sources is not always known, an argument put forth by the pharmaceutical industry is that DTC advertising encourages patients to take more questions to their doctors, and this may be a benefit rather than a disadvantage. Another argument for receiving



information through the lay media or advertising is that it encourages patients to become partners in their own healthcare.³²

As the public becomes aware of both conventional and CAM modalities, healthcare providers should ask their patients about their use of CAM. In order to safeguard a patient's health, these questions should be asked during the initial history-taking and should be repeated at regular intervals. For cancer patients, this information can be critically important as it can reveal that the patient is taking herbs or other substances that may interfere with conventional therapy or alter laboratory values. The conventional provider may also be a source of information on CAMs that are not harmful and can offer the cancer patient a level of comfort not achieved by conventional therapy alone.

GOAL PA-3 To increase awareness of the benefits and risks of CAM use in palliative care.

Objective PA-3.1

To increase awareness among healthcare professionals of the benefits and risks of CAM use in palliative care.

Strategy

PA-3.1.1 Integrate training on CAM in palliative care into primary and continuing education for practicing professionals.

Objective PA-3.2

To increase awareness among the public of the benefits and risks of CAM use in palliative care.

Strategy

PA-3.2.1 Develop a public education plan on CAM in palliative care for targeted populations based on capacity and needs assessments.



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