Abstract

As management of patients with cancer is evolving, an increased focus is being placed on individualized patient-centered care. Early integration of palliative care into the overall management of patients with cancer can help achieve this paradigm shift. Despite recommendations for earlier integration of palliative care by national and international societies, several barriers remain to achieving this goal. Survey studies have indicated a significant need for increased education regarding palliative care for both medical undergraduates and postgraduate physicians. Key issues in the early integration of palliative care include relationship-building across multiple health systems and specialties; development of a standardized definition of palliative care, making clear that it should be fully integrated with cancer-directed therapy; identification of physician and nonphysician champions; standardization of tools for patient assessment; education programs designed to meet the needs of health care professionals; and ongoing evaluation to assess program benefits and limitations. (JNCCN 2013;11(Suppl 1):S11–S16)

Barriers and Approaches to the Successful Integration of Palliative Care and Oncology Practice

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The importance of palliative care is increasingly being recognized in the management of patients with cancer, with clear evidence that earlier initiation of palliative care can significantly improve quality of life and potentially even survival in patients with cancer. The recognition that palliative care is an essential component of optimal cancer care and that it should be integrated as early as possible into the overall management regimen is further supported by statements from multiple groups focused on cancer treatment. The WHO considers palliative care to be “an approach that improves the quality of life of patients and their families through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.” The recently published ASCO provisional clinical opinion states that combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden. The Associazione Italiana di Oncologia Medica has stated that “taking care of patients with cancer means not only to offer them the best therapeutic options but also to understand and anticipate their physical, functional, psychological, social, and spiritual needs throughout the course of the disease.” Achievement of the best possible quality of life of a patient with cancer, a fundamental goal at every step on the disease trajectory, is best addressed through supportive palliative care and rehabilitation. The ESMO Program for the Integration of Oncology and Palliative...
Barriers to Integration of Palliative Care

Perception of Palliative Care as Distinct From Other Interventions in Patients With Cancer

Perhaps the most significant barrier to the integration of palliative care at all stages in the treatment of patients with cancer is the perception that it is end-of-life care.\(^7\,8\) An assessment of perceptions and experiences of palliative care providers indicated that some health care professionals viewed palliative care as being primarily focused on symptom control for terminal patients. These professionals saw palliative care as a consideration only after all disease-modifying treatment had ceased.\(^9\) These misperceptions are supported by other studies.

Results from a survey of medical oncologists and other health care professionals in the United States indicated that the term palliative care was considered to be synonymous with hospice and end-of-life care by nearly 60% of participants.\(^10\) It was also noted that the term itself was a barrier to referral by 23% of respondents. The term supportive care rather than palliative care was thought to be more likely to prompt referral of patients with newly diagnosed cancer or undergoing active therapy (both \(P<.0001\)) among those surveyed.\(^10\) Although the name given to the services provided might be viewed as unimportant, in actual clinical practice, a second study indicated that the name change from palliative care to supportive care resulted in a significant increase in the number of patients referred for treatment (\(P<.001\)). In addition, results showed a significant increase in the percentage of patients with early-stage cancer referred for supportive care (\(P<.001\)), a significantly shorter interval between hospital registration and supportive care consultation (\(P<.001\)), and a significantly shorter time between advanced cancer diagnosis and supportive care consultation (\(P<.001\)).\(^11\)

The preceding studies illustrate that perception of a service can alter use. However, although changing the name may placate patient or health care provider discomfort over the concern that the disease must be getting worse (even when that is not the case), the optimal approach is to provide better education about what palliative care is and is not. Palliative care is not just end-of-life or hospice care. In a prospective, randomized, controlled trial in which patients with metastatic non–small cell lung cancer were referred for early palliative care services (still using the term palliative care) versus standard oncologic care, the patients referred systematically to the palliative care team experienced significant improvements in quality of life and mood.\(^1\) Therefore, defining the breadth and scope of palliative care services is an important step to optimizing referral and use of services. Palliative care can be considered as “medical care focused on the relief of suffering and support for the best possible quality of life for patients facing serious, life-threatening illness and their families,” and “aims to identify and address the physical, psychological, and practical burdens of illness [and it] may be delivered simultaneously with all appropriate curative and life-prolonging interventions.”\(^12\)

Physician Attitudes Regarding Expertise Required for Effective Delivery of Palliative Care Services

Although many physicians believe that they are providing effective pain relief, results from 2 physician surveys, conducted 20 years apart, demonstrate otherwise. A survey of ECOG physicians in 1990 indicated that only 51% believed that pain control in their own practice was good or very good. Unfortunately, survey results also showed that 31% of respondents would not initiate maximal analgesia until the expected survival of the patient was less than
A 2010 survey of oncologists indicated the belief that they provided effective pain relief for their patients; of 482 responses to a question regarding how well medical oncologists perform in relieving cancer pain, the median score was 7 (based on a numeric rating scale of 0–10, with higher numbers signifying better). However, when presented with 2 clinical vignettes regarding pain management, 87% provided incorrect responses to the first, and 60% gave unacceptable responses to the second. Results of these surveys provide evidence that, in clinical practice, pain remains inadequately treated.

**Referral Patterns Reflect Physician Beliefs and Attitudes**

Multiple surveys indicate that palliative care services for patients with cancer are underused. One survey of 699 cancer specialists revealed that only 48% referred more than 60% of their patients for specialized palliative care services. The most frequent reasons for referral were current or anticipated requirement for symptom control or terminal illness. Results from a survey of 155 physicians caring for patients with lung cancer indicated that 48% of physicians referred fewer than 25% of their patients for palliative care consultation. A major reason for this low referral rate was concern that a palliative care referral would alarm patients and families. In fact, 16% of oncologists never referred patients for palliative care, 68% did so rarely or occasionally, and only 16% referred patients frequently. Furthermore, palliative care services for the pediatric population are limited. Only 58% of institutions in the multinational Children’s Oncology Group have a palliative care team.

**Increasing Early Integration of Palliative Care**

To increase the early integration of palliative care into oncology practice, education to improve the understanding of the goals of palliative care and the range of interventions encompassed by this aspect of cancer patient management is essential. This education should begin at the earliest stage of training for health care professionals. Results from an evaluation of 101 final-year medical students in Germany reported that only one-third answered correctly more than 50% of 21 questions about palliative care. In addition, “only 5% to 10% declared a high level of confidence in dealing with palliative care issues.”

Similar survey results from 176 medical students in The Netherlands showed that only 35% rated their education in palliative care as good. Results are not terribly different for more-advanced trainees. In a survey of 120 hematology-oncology fellows attending the 2004 annual ASCO meeting, respondents reported that their knowledge of issues related to palliative care (eg, appropriate administration of opioids) was poor. Only 42% rated their fellowship education regarding palliative care as very good or excellent.

Larger studies of residency training support these findings. An assessment of palliative care and end-of-life education at 32 accredited internal medicine residency programs in the United States indicated that all of them included some end-of-life education. However, training in pain assessment and treatment was provided in only 60% of programs and fewer than 30% provided education on the management of symptoms other than pain.

**Benefits of Palliative Care Education**

Efforts have been made to provide education aimed at improving palliative care for patients with cancer. Studies that have evaluated the outcomes of these interventions show significantly improved patient care.

One intervention aimed at improving palliative care enrolled 253 residents, interns, and medical students from 3 primary care training programs into an elective that included clinical training in an acute hospital palliative care consult service, an inpatient hospice and palliative care unit, and an in-home hospice care service. Topics addressed in the program included principles of hospice and palliative medicine, breaking bad news, cancer pain, nausea and vomiting, symptoms of advanced illness, diagnostic and therapeutic procedures, terminal illness, and managing personal stress. All of the trainees who participated in the program took a 25-question pre- and posttest. Results indicated a 10% improvement \((P<.05)\) on test performance after completion of the elective. A qualitative review confirmed that participants found the elective to be valuable.

A much less intensive program at Boston University School of Medicine was also shown to improve competence. This 1-week curriculum
included an orientation to hospice care, core articles, and home hospice visits. Knowledge and attitudes before and after the program were assessed with pre- and post-activity questionnaires. Results from 45 participants indicated significant improvements in attitudes and self-assessed knowledge of “appropriate” end-of-life care (P<.05).25

Online education has also been shown to improve physicians’ knowledge of palliative care. A group from Spain developed an online palliative care educational model aimed at primary care physicians. Four modules provided information on the overall concept of palliative care, comprehensive patient assessment, pain evaluation and treatment, management of other nonpain symptoms (eg, respiratory, neuropsychiatric, urinary, asthenia, and anorexia), delivery of bad news, and assessment of quality of life. The effects of the online education were evaluated in 169 physicians (85 in the intervention group and 84 in the control group). Outcome assessment indicated significant improvement with respect to knowledge (P=.0001), confidence in ability to manage symptoms (P=.02), and confidence regarding communication with patients and families (P=.038).24

Large-Scale Integrated Interventions to Improve Palliative Care

Several large-scale interventions have been developed and implemented to improve the delivery of palliative care. The Education in Palliative and End-of-Life Care (EPEC) program was developed to increase knowledge in palliative care using an approach and content based on adult education theory that emphasizes interactive techniques.26 The EPEC program incorporates principles from the social sciences and is aimed at altering social expectations and behavioral norms. The material is presented in 16 modules and 4 plenaries that use both slides and videos. As illustrated in Figure 1, the program models a continuum of comprehensive care, whereby services provided change with the course of the illness. Evaluation of the EPEC program by 200 physicians who were trained to use the curriculum indicated that 62% believed that it greatly improved their knowledge of end-of-life care and 72% believed that it greatly improved their ability to teach others about the subject. In addition, of the 184 physicians who used the EPEC curriculum for teaching, 96% of them planned to continue or increase their end-of-life care training activity.27

A subsequent initiative, the Education in Palliative and End-of-Life Care for Oncology (EPEC-O) program, was developed specifically for clinicians caring for patients with cancer. This program is a comprehensive, multimedia, train-the-trainer curriculum in palliative and end-of-life care (eg, pain and symptom management, care planning, and communication). The EPEC-O program, which is available free through the NCI, includes 3 plenary sessions, 15 self-study modules, materials for trainers, video vignettes, and clickable citations.28

Building on the success of programs such as EPEC, the aim of the Advocating for Clinical Excellence (ACE) Project is to improve the delivery of palliative care through an intensive advocacy and leadership training program for 300 psycho-oncology professionals. Course content includes information on value-based training, palliative care delivery, and leadership and advocacy skills. Assessment of the effectiveness of the program in an initial cohort of 145 participants indicated significant self-reported improvement in skills related to palliative care and leadership (P<.001).29

Some countries have developed structured systems for education in palliative care and/or pain management on a national level. For example, in France, an educational program emphasizes appropriate pain management at all stages of cancer care. It is performed at public and private hospitals and outpatient facilities. The program has focused on surgical and cancer pain and has included both elderly and pediatric patients. It includes 2 structured educational programs: 1) a General Education in Medical Sciences diploma; and 2) a master’s program focused on competence in pain management and processes.30

A law recently passed in Germany mandates that by 2013, all medical students will have palliative medicine education as a compulsory component of their curriculum.31 Germany also established a national standardized palliative care documentation tool called Hospice and Palliative care Evaluation (HOPE) in 1996, which resulted in an ongoing national registry of data for the assessment of palliative care.32
Integrating Delivery of Palliative Care

The development and implementation of palliative care initiatives focused on its integration across the continuum of disease provide key insights into the necessary steps to achieve this goal. Relationship building across multiple health systems is essential to achieve integration of palliative care throughout the course of disease. Implementation of valid and reliable tools for symptom screening and assessment, steps to maximize symptom control, and efforts to coordinate continuity of care between health care settings are all required. A systematic approach combined with coordination of care and use of quality improvement strategies has substantially improved the screening and management of symptoms and the functional assessment of patients with lung cancer throughout the regional cancer centers in Ontario, Canada. The optimal timing of palliative care interventions during the course of illness may vary based on the malignancies. A German working group has developed guidelines focused on disease-specific timing for integrating palliative care into oncology care.

Conclusions

Integration of palliative care can help achieve the paradigm shift from a disease-focused approach to patient-centered care. WHO, ASCO, and ESMO agree that palliative care is an essential component of optimal cancer care.

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