Palliative Cancer Care a Decade Later: Accomplishments, the Need, Next Steps—From the American Society of Clinical Oncology

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ABSTRACT

Purpose
In 1998, the American Society of Clinical Oncology (ASCO) published a special article regarding palliative care and companion recommendations. Herein we summarize the major accomplishments of ASCO regarding palliative cancer and highlight current needs and make recommendations to realize the Society’s vision of comprehensive cancer care by 2020.

Methods
ASCO convened a task force of palliative care experts to assess the state of palliative cancer care in the Society’s programs. We reviewed accomplishments, assessed current needs, and developed a definition of palliative cancer. Senior ASCO members and the Board of Directors reviewed and endorsed this article for submission to Journal of Clinical Oncology.

Results
Palliative cancer care is the integration into cancer care of therapies that address the multiple issues that cause suffering for patients and their families and impact their life quality. Effective provision of palliative cancer care requires an interdisciplinary team that can provide care in all patient settings, including outpatient clinics, acute and long-term care facilities, and private homes. Changes in current policy, drug availability, and education are necessary for the integration of palliative care throughout the experience of cancer, for the achievement of quality improvement initiatives, and for effective palliative cancer care research.

Conclusion
The need for palliative cancer care is greater than ever notwithstanding the strides made over the last decade. Further efforts are needed to realize the integration of palliative care in the model and vision of comprehensive cancer care by 2020.

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INTRODUCTION

In 1998, the American Society of Clinical Oncology (ASCO) published the special article “Cancer Care at the End of Life”1 and a companion article “Consensus Statement of Recommendations for High-Quality Cancer Care Developed by the American Federation of Clinical Oncologic Societies”.2 In the succeeding 10 years, remarkable progress has been made to overcome the barriers to the integration of palliative care into cancer care, to increase knowledge and skills, and to improve the experience of patients and families.

This article summarizes the major accomplishments of ASCO, its members, and other stakeholders during the past decade. It then highlights the need for palliative care in 2008 and presents recommendations for next steps for ASCO and its members to realize ASCO’s vision of comprehensive cancer care by 2020.
Palliative Cancer Care a Decade Later

Board then reviewed and agreed to the recommendations and this article.

Accomplishments

The significant accomplishments of ASCO, its members, and other stakeholders since the publication of the special article “Cancer Care at the End of Life” in 1998 follow.

Clinical accomplishments. ASCO, at that time, concluded that the "provision of optimal end-of-life care requires access to and the availability of state-of-the-art palliative care rendered by skilled clinicians, buttressed when necessary, by palliative care experts." ASCO recognized “that hospice is a widely available and excellent model for managing end-of-life care and should be better utilized.” While this remains true, the provision of palliative care has expanded from a focus on end-of-life care to a comprehensive model of care in which palliative care is integrated throughout the illness experience.

Advocacy and policy statements. Since 1997, numerous organizations issued statements advocating for palliative care to be a part of comprehensive cancer care. In the United States, the Institute of Medicine (IOM) published a series of documents characterizing the role of palliative care within comprehensive cancer care (Table 1). Internationally, the WHO as well as the International Narcotics Control Board and other agencies advocated for palliative care as an integral part of cancer care.

In 2005, the 58th World Health Assembly fully integrated palliative care into its resolution WHA58.22 to improve Cancer Prevention and Control. This resolution recognized palliative care as an essential component of comprehensive cancer care, equal to medical, surgical, and radiation oncology and urged member nations to fully integrate palliative care into their national cancer control programs.

In 2006, the ASCO Board of Directors approved an ASCO-European Society of Medical Oncology (ESMO) Consensus Statement on Quality Cancer Care. This 10-point statement listed common goals to ensure access to, and the continuity of, high-quality cancer care. It included pain management, supportive, and palliative care.

Integration of palliative care. Over the past 10 years, ASCO members have developed several innovative models integrating palliative care into cancer care. As an example, the University of Texas M. D. Anderson Cancer Center (Houston, TX) has been integrating palliative care into its outpatient and inpatient services. Across the United States, institutions have begun to formally integrate palliative care in their oncology programs and some large community practices are also hiring palliative care physicians to enhance their services. This activity is mirrored by many programs worldwide.

Use of hospice services. ASCO’s special article “recognized hospice as a widely available, but underutilized, excellent model for delivering end of life care”. Since 1998, the use of hospice services in the United States has more than doubled, from 540,000 patients served in 1998 to 1,300,000 in 2006. Although there has been an overall increase in the use of hospice services, ASCO has not actively pursued strategies that would increase acceptance and lead to earlier referral to afford patients and families optimal value from the Medicare Hospice Benefit and other hospice-related health care coverage.

Development of standards, guidelines, and quality improvement strategies. Before its 1998 special article, ASCO published and disseminated guidelines on cancer pain assessment and treatment (1992) and the use of hematopoietic colony-stimulating factors (1994). Throughout the past decade, ASCO has published seminal guidelines related to palliative care (Table 2).

To foster the integration of palliative care into oncology practice, ASCO has already incorporated several of the measures outlined in the National Quality Forum’s Preferred Practices for Palliative and Hospice Care (2006) into its Quality Oncology Practice Initiative (QOPI).

To encourage the integration of palliative care into cancer centers, ESMO has promoted standards for palliative care and provided awards for outstanding performance. WHO and the National Comprehensive Cancer Network (NCCN) have developed consensus-based guidelines on palliative care, and the NCCN has developed guidelines in several specific areas of supportive care that are available on its Web site.

To promote the appropriate use of controlled substances in the management of chronic cancer and noncancer pain, the Federation of State Medical Boards developed a Model Policy for the Use of Controlled Substances for the Treatment of Pain in 2004.

Educational accomplishments. Even in 1998, ASCO believed “that educational initiatives directed at optimizing the physician’s clinical and psychological skills in delivering end-of-life care are essential and must be directed at the medical students, pediatric and medical residents, oncology trainees from all disciplines, practicing oncologists, and allied members of the health care team.”

In 1998, ASCO surveyed its members and learned that 90% of the 3,227 medical, surgical, radiation, and pediatric oncologists who responded learned about palliative care through trial and error. In 1998, ASCO published a Model Policy for the Use of Controlled Substances for the Treatment of Pain in 2004. Educational resources. In 2001, ASCO published the curriculum Optimizing Cancer Care: The Importance of Symptom Management. This educational resource was developed for use in oncology training programs as well as for continuing medical education; patient education materials based on this curriculum are also available.

In 2004, ASCO developed Oncology MKSAP, a self-study tool consisting of 19 chapters, one of which was devoted to supportive care. The Society followed up this resource with ASCO-SEP: Medical Oncology Self-Evaluation Program, which provides information on assessing and mitigating potential symptoms that negatively affect quality of life.

Table 2. American Society of Clinical Oncology Guidelines Relating to Palliative Care 1999 to 2007

<table>
<thead>
<tr>
<th>Year</th>
<th>Guideline</th>
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<tbody>
<tr>
<td>1999</td>
<td>Recommendations for the Use of Antiemetics</td>
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<td>1999</td>
<td>Use of Chemotherapy and Radiotherapy Protocols</td>
</tr>
<tr>
<td>2001</td>
<td>Platelet Transfusion for Patients with Cancer</td>
</tr>
<tr>
<td>2003</td>
<td>Update on the Role of Bisphosphonates and Bone Health Issues in Women With Breast Cancer</td>
</tr>
<tr>
<td>2003</td>
<td>Treatment of Unresectable Non–Small-Cell Lung Cancer Guidelines</td>
</tr>
<tr>
<td>2006</td>
<td>Use of Larynx-Preservation Strategies in the Treatment of Laryngeal Cancer</td>
</tr>
<tr>
<td>2007</td>
<td>Update on the Role of Bisphosphonates in Multiple Myeloma</td>
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<tr>
<td>2007</td>
<td>Update on the Role of Bisphosphonates in Multiple Myeloma</td>
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<tr>
<td>2007</td>
<td>Endorsement of the Cancer Care Ontario Practice Guideline on Nonhormonal Therapy for Men With Metastatic Hormone-Refractory (castration-resistant) Prostate Cancer</td>
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</tbody>
</table>
In 2005, ASCO published in the *Journal of Clinical Oncology* (JCO) the second edition of the ASCO Core Curriculum Outline (ACCO), a framework for training medical oncologists, which includes the integral topics in palliative care and psychosocial issues related to cancer.

In 2005, ASCO supported the launch of the Education in Palliative and End-of-life Care for Oncology (EPEC-Oncology) Curriculum in collaboration with the National Cancer Institute (NCI), The EPEC Project, and the Lance Armstrong Foundation. This comprehensive curriculum is available free from NCI with continuing medical and nursing education credits provided by ASCO and is available for self-study online from the EPEC Project. From October 1, 2006, through March 31, 2007, more than 20,000 health professionals (6,438 physicians and 12,392 nurses/advance practice nurses) reviewed the Last Hours of Living module and completed the evaluation for continuing education credits. In its first 3 months that the module on Withdrawing Nutrition and Hydration was online in early 2008, more than 10,885 people, including 1,352 physicians, completed the continuing education activity for credit.

ASCO meetings. The ASCO Annual Meeting, which serves more than 30,000 attendees each year, regularly incorporates palliative care sessions into both the education and research tracks. As an example, a 2002 education session on advanced laryngeal cancer included a presentation by a palliative care expert. Programs highlighting palliative cancer care presented as part of the Annual Meeting are displayed in Table 3. Education and scientific sessions from the Annual Meeting are also available in the ASCO Virtual Meeting section of ASCO.org and as enduring materials in the *Educational Book* from each Annual Meeting.

Nationally: Recognizing the burden of adverse effects of cancer and its treatment, ASCO cosponsored a 1-day symposium with the IOM to disseminate the conclusions and recommendations of the IOM report, "From Cancer Patient to Cancer Survivor: Lost in Transition." The symposium highlighted the short- and long-term impairments suffered by cancer survivors—physical, psychological, and functional—and their impact on quality of life. Furthermore, ASCO convened a Survivorship Task Force committed to integrating survivorship concerns into all of ASCO's scientific and educational activities. Evidence-based guidelines, focused on palliative care issues important to survivors, have been published (fertility preservation, cardiac and pulmonary late effects of adult cancer survivors) and others are planned. In collaboration with the National Coalition for Cancer Survivorship, ASCO is working to improve the quality and the delivery of care for survivors. Internationally, ASCO has partnered with national cancer societies in other countries (eg, Egypt, Spain, and Latin America) to present courses that both incorporate and feature palliative care cancer care. For example, the Multidisciplinary Cancer Management Courses includes a module on end-of-life care.

Publications. Since its inception as ASCO's official journal (1983), more than 700 articles related to palliative care have been published in *Journal of Clinical Oncology* (JCO); Appendix Table A1, online only). In 1999, JCO focused a *Classic Papers and Current Comments* issue on supportive care. In 2000, *The Art of Oncology – When the Tumor Is Not the Target* debuted as a monthly feature. A decade later, JCO has published another special review series issue on improving the quality of supportive cancer care (August 10, 2008, volume 26, issue 23).

<table>
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<tr>
<th>Table 3. ASCO Annual Meeting: Palliative Care Programs</th>
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<tr>
<td><strong>Meeting</strong></td>
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<tr>
<td>ASCO Presidential symposium</td>
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<td>Karnofsky lecture</td>
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<td>Symposia</td>
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<tr>
<td>MASCC/ASCO symposium</td>
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<tr>
<td>Special sessions</td>
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Abbreviations: ASCO, American Society of Clinical Oncology; MASCC, Multinational Association of Supportive Care in Cancer.

There are now more than 10 specialty journals focused only on palliative care that routinely publish articles related to palliative care and cancer, and many ASCO members have written editorials in these journals to describe and justify the need for research and articles in this field.

Fellowship training. While ASCO has not yet advocated for palliative care to be a component of oncology fellowship training, ASCO's yearly in-training exam for oncology fellows, launched in 2008, includes questions about palliative care.

The American Board of Internal Medicine advocates for inclusion of palliative care as a component of internal medicine training, including medical oncology. As of 2008, 7% of the questions on the medical oncology certification examination are related to supportive care and ethics.

In the scope of radiation oncology practice, American Society of Therapeutic Radiology and Oncology strongly supports the need for expertise in palliative care, given that nearly half of patients treated with radiotherapy receive treatment with palliative intent.

Recognition of palliative medicine as a specialty. Palliative care has been formally recognized as a medical specialty in Australia, Israel, the United Kingdom, and the United States.

In 2006, 10 of 24 boards of the American Board of Medical Specialties unanimously cosponsored the new specialty of Hospice & Palliative Medicine, including Anesthesiology, Family Medicine, Internal Medicine (including Hematology and Medical Oncology), Emergency Medicine, Pediatrics (including Pediatric Oncology), Radiology (including Radiation Oncology), Surgery (including Surgical Oncology), OB-GYN (including gynecologic oncology), Psychiatry/Neurology, Physical Medicine and Rehabilitation (including Cancer Rehabilitation). This historical precedent explicitly acknowledges that the unique knowledge and skills of palliative care are shared by each of these disciplines.

Research accomplishments. In 1998, the ASCO special article outlined a research agenda calling for "Research on the Physical, Psychological, and Socioeconomic Problems That Are Presented by the Terminal Phases of Illness." Even then, ASCO believed "that clinical decisions based on reliable evidence represent the most practical way to assure high-quality and compassionate end-of-life initiatives on outcomes, predictors and interventions during the end phase of terminal illness, including": pain and other physical symptoms; depression and other mental health symptoms; spirituality and existential meaning; communication; caregiving burdens; and economic burdens.

Over the past 10 years, a range of new oncology drugs and therapies aimed at symptom control have come to market. The majority of the research and development of these products have been funded by industry. Fewer than 3% of all National Institutes of Health (NIH) funding has been directed toward palliative care research.

For many years, ASCO has incorporated a patient care track into the ASCO Annual Meeting for the presentation of clinical trials and research related to palliative and supportive care in the broadest sense. Since 1998, ASCO has given a number of Career Development Awards and Young Investigator Awards to junior researchers investigating palliative care topics. A review of the 130 Career Development Awards topics funded since 1992 revealed that approximately 8% related to palliative care issues.

Need for Palliative Care

An aging population with its associated growing incidence and prevalence of cancer makes palliative care a public health issue as well as a cancer care issue. Each year, 10 million people worldwide are diagnosed with cancer and 6 million die from the disease. Global cancer rates will increase by 50%, from 10 million in 2002 to 15 million cases in 2020. In the developed world, this increase in incidence has been accompanied by a dramatic increase in the number of cancer survivors who live with treatment and cancer-related disabilities and symptoms. Fifty percent of the world’s new cancer cases occur in developing countries; in 80% of these cases, disease is incurable at the time of diagnosis and most patients will die within 1 year. More than one half of the 600 million individuals older than 60 years live in developing countries. By 2020, the proportion of the population over 60 years will be 23% in Europe and North America.
The need for palliative care as a part of comprehensive cancer care in the United States is no different from the rest of the world. While the United States cure rate for cancer looks better than for the rest of the world, this is mostly due to preventive measures (smoking cessation), early detection (mammograms, colonoscopy), and surgical approaches to cure. Half of all cancers in the United States is no different from the rest of the world. While the United States experience of cancer in 2008. Since the introduction of antibiotics (eg, penicillin) in the early 1940s and the development of extensive medical, radiation, and surgical treatments for cancer and other diseases, the average life expectancy in North America and much of Western Europe has increased by 20 years in just 70 years. For many patients who are surviving with cancer for months to years, it has become a chronic illness.

Of the patients with advanced cancer, at least 60% will experience moderate to severe pain that requires opioids to control it. Pain rarely occurs in isolation; most patients live with multiple issues that are the manifestations (eg, symptoms, dysfunction) and predicaments (eg, change in roles, financial concerns, dependence) created by their underlying disease and its treatment (Fig 1). The experience of cancer has a profound impact on both patients and their families.

Palliative cancer care is the integration into cancer care of therapies to address the multiple issues that cause suffering for patients and their families and have an impact on the quality of their lives. Palliative cancer care aims to give patients and their families the capacity to realize their full potential, when their cancer is curable as well as when the end of life is near.

In the 1998 special article, ASCO described “the oncologists’ responsibility to care for their patients in a continuum that extends from the moment of diagnosis throughout the course of the illness. In addition to appropriate anticancer treatment, this includes symptom control and psychosocial support during all phases of care, including those during the last phase of life”. The model of cancer care is no longer a model of cure versus comfort (Fig 2).

Focus of Care Anticancer therapy (curative, life-prolonging, or palliative intent) Palliative Cancer Care Bereavement Care

Diagnosis Time 6-Month Prognosis Death

Acute Chronic Advanced Life-Threatening Illness Bereavement

Fig 2. Model of palliative care.
of comprehensive cancer care by 2020. ASCO will collaborate with other US policies that incorporate palliative cancer care are essential to the development advocating legislative and regulatory changes that will eliminate these barriers.

Recommendations

To achieve this vision of comprehensive cancer care by 2020 consistent with the WHO Strategy for integrating palliative care into cancer care, ASCO recommends changes in policy, drug availability, education, the integration of palliative care throughout the experience of cancer, quality improvement initiatives, and research. ASCO is committed to informing its membership and the public about the significant barriers to optimal palliative cancer care and to advocating legislative and regulatory changes that will eliminate these barriers.

Policy. ASCO believes that national and international oncology control policies that incorporate palliative cancer care are essential to the development of comprehensive cancer care by 2020. ASCO will collaborate with other US and international oncology stakeholders to advocate for the integration of palliative cancer care into existing health care systems and national cancer control plans; and advocate for adequate funding to ensure that all patients have access to high-quality palliative cancer care, including the medications, therapies, and services they need.

Drug availability. ASCO believes that access to the medications and therapies needed to provide palliative cancer care, including opioids, is essential to realize comprehensive cancer care. The WHO List of Essential Medicines designates the minimum medications that should be available for the provision of high-quality palliative cancer care. Where resources permit, a much wider scope of medications and therapies should be available. ASCO will collaborate with national and international stakeholders, including the International Narcotics Control Board, to ensure the availability of, and access to, adequate supplies of essential medicines, including opioids.

Education. Building on beliefs expressed in the 1998 special article and the accomplishments in the decade since then, ASCO endorses the following palliative cancer care objectives to be fully achieved during the next 10 years. Work on these objectives has already begun in many instances: update existing palliative cancer care educational resources and make them readily available to members and other oncology stakeholders worldwide (eg, through ASCO.org); translate these palliative cancer care educational resources into the other official United Nations languages; develop and disseminate educational materials related to palliative cancer care to support oncology fellowship training programs; provide technical support to the program directors to integrate palliative cancer care into oncology fellowship programs; develop and disseminate a list of institutions with comprehensive palliative cancer care programs that will accept oncology fellowship trainees; advocate to the Accreditation Council for Graduate Medical Education the mandatory inclusion of 1-month rotations in palliative cancer care during oncology fellowship; increase the number of questions on the ASCO fellowship in-training exam to assess candidate preparedness to provide effective palliative cancer care; consider the development of educational resources to help palliative medicine fellows and specialists understand oncology diagnosis, prognosis, and treatment; standardize the palliative cancer care–related terminology that is commonly used in oncology clinical trials and ASCO publications, (eg, best supportive care, palliative chemotherapy).

ASCO also will undertake the following to be achieved during the next 10 years: fully integrate palliative cancer care into the Society’s annual and the matings and courses; create education and research tracks specific to palliative cancer care into the Annual Meeting, including designated oral and poster sessions; work toward sponsorship of an award to support innovative palliative cancer care education; continue to expand its partnerships with national cancer societies in other countries by increasing the palliative cancer care content in existing courses (eg, Multidisciplinary Cancer Management Courses) and presenting courses specific to palliative cancer care.

Integration of palliative cancer care. To realize the vision of comprehensive cancer care by 2020 and build on the belief that quality cancer care “requires access to and the availability of state-of-the-art palliative cancer care rendered by skilled clinicians, buttressed when necessary, by palliative care experts”, ASCO envisions: development and dissemination of effective models of comprehensive cancer care that incorporate palliative cancer care; highlighted focus on cancer centers and regional cancer programs that are successfully integrating palliative cancers successfully integrating palliative cancer care into their services; recognition of excellence in palliative cancer care delivery with an award similar to the Clinical Trials Participation Award; highlighted resources and organizations that are prepared to help cancer centers integrate palliative cancer care (eg, the NCI-funded Disseminating End-of-Life Education to Cancer Centers Project).

Quality improvement. To ensure that the palliative cancer care received by patients and families is high quality and consistent, ASCO also prioritizes the following objectives: development of new evidence-based practice guidelines on topics germane to palliative cancer care in the areas where there is sufficient evidence, with consideration of such topics as the management of anorexia, dyspnea, fatigue, psychosocial support, and existential distress; dissemination and highlighting of existing standards, guidelines, measures, and outcomes that can be useful in improving and assessing the effectiveness of palliative cancer care; development of additional QOPI measures to evaluate

Table 4. Skills for Providing Palliative Cancer Care

<table>
<thead>
<tr>
<th>Step No.</th>
<th>Action</th>
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<tbody>
<tr>
<td>1</td>
<td>Assessment*</td>
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<tr>
<td>2</td>
<td>Information sharing*</td>
</tr>
<tr>
<td>3</td>
<td>Decision making*</td>
</tr>
<tr>
<td></td>
<td>Determination of capacity*</td>
</tr>
<tr>
<td></td>
<td>Discussing goals of care*</td>
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<tr>
<td></td>
<td>Requests for withdrawing/withdrawing therapy*</td>
</tr>
<tr>
<td></td>
<td>Requests for physician-assisted suicide*</td>
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<tr>
<td></td>
<td>Advance care planning*</td>
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<td></td>
<td>Surrogate decision-making*</td>
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<td></td>
<td>Conflict resolution*</td>
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<tr>
<td>4</td>
<td>Care planning</td>
</tr>
<tr>
<td>5</td>
<td>Care delivery</td>
</tr>
<tr>
<td>6</td>
<td>Confirmation of understanding, satisfaction, concerns</td>
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</tbody>
</table>

NOTE. During each therapeutic encounter, the process for providing care involves six essential steps that guide the interaction between caregivers, and the patient and family.

*Discussed in the Education in Palliative and End-of-Life Care for Oncology curriculum.

Vision for Comprehensive Cancer Care in 2020

By 2020, the United States and several other countries have national cancer control plans that include palliative care as a routine part of comprehensive cancer care for all patients. These services are available in every cancer center around the country. Just as growth factors and antibiotics are routinely administered to prevent neutropenic fever, consistent palliative cancer care is consistently delivered to prevent and relieve the suffering of patients and families from the day of diagnosis. The medications needed to provide palliative cancer care are readily available, without cost to the patient or family.

Oncologists have the knowledge and skills they need to understand the biologic science of cancer and its treatment and the psychologic and social sciences they need to care for patients and their families. They are supported by a skilled interdisciplinary team of nurses, social workers, psychologists, and spiritual counselors who are able to share much of the burden of the patient’s, the family’s, and the team’s suffering. They also foster the search for meaning and value in the care the team is providing. Oncology caregivers are professionally and educationally supported as the deliverers of compassionate care; the issue of burnout and compassion fatigue are understood and addressed.

ASCO’s educational materials, meetings, and courses seamlessly integrate new palliative cancer care concepts with advances in cancer management strategies. These resources are easily accessible to ASCO members and oncology trainees through a variety of media. The high quality of research in palliative cancer care is reflected by abstracts selected for plenary sessions and discussion in highlights sessions. Palliative cancer care is an integral part of oncology fellowship training and the certification examination. ASCO’s advocacy for funding strategies has led to a number of innovative palliative cancer care research initiatives and publications. Young investigators see this field as an attractive research career opportunity as the number of questions on the ASCO fellowship in-training exam to assess candidate preparedness to provide effective palliative cancer care; consider the development of educational resources to help palliative medicine fellows and specialists understand oncology diagnosis, prognosis, and treatment; standardize the palliative cancer care–related terminology that is commonly used in oncology clinical trials and ASCO publications, (eg, best supportive care, palliative chemotherapy).

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The worldwide need for palliative care to relieve the suffering of patients and families living with cancer is greater than ever. Over the past decade, ASCO, its members, and other stakeholders have made strides to meet the recommendations published in ASCO’s Special Article “Cancer Care at the End of Life” in 1998. ASCO recognizes that further efforts are needed and is committed to facilitating the integration of palliative care into existing health care systems worldwide in order to realize the vision of comprehensive cancer care by 2020.

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