

ESMO Policy on Supportive and Palliative Care

N. I. Cherny¹, R. Catane², P. A. Kosmidis³ and Members of the ESMO Palliative Care Working Group⁴

For further information:

chernyn@netvision.net.il

Introduction

Traditionally, the study and practice of medical oncology has focused on the development and implementation of primary anti-cancer therapies. By virtue of these endeavors, along with measures to provide for early diagnosis, substantial improvements in long- and short-term survival have been achieved for a number of cancers such as germ cell tumors, lymphomas, early-stage breast and colorectal cancer, and the leukemias. More sobering, however, are the observations that the cure rate for cancer remains at <50% and that cancer continues to account for >25% of all adult deaths [1]. Many patients are not cured, and for them the issues regarding the quality of their remaining time are critical, irrespective of the clinical course of their illness or the duration of survival.

More than 10 years have passed since the expert committee of the World Health Organization (WHO) on cancer pain and palliative care handed down its report, which called for the integration of efforts directed at maintaining the patient's quality-of-life in all stages of cancer treatment [2]. That report emphasized that factors causing patient distress exist from the time of diagnosis onward and that supportive interventions are needed concurrently with efforts to control the underlying cancer; this holds true for patients undergoing both curative and palliative anti-cancer treatments.

This view is endorsed by the European Society for Medical Oncology (ESMO), which is committed to excellence in all aspects of oncological care. As the prime cancer specialist, the medical oncologist coordinates cancer care in all of its phases. This reflects ESMO's commitment to continuity of care. Against a background of advanced cancer, and among cancer patients approaching the end of life, this requires close coordination of palliative care to optimize the quality-of-life and to ensure the comfort of dying patients. This is a moral and clinical imperative. In 1999, ESMO established a special working group, chaired by Professor Raphael Catane, to improve both the quality of supportive and palliative care delivered by medical oncologists and coordination with other supportive and palliative care clinicians. This working group recognized that there is often confusion over the meaning of the terms palliative care, supportive care, and terminal care. To clarify matters, the group's members devised a series of pragmatic definitions, which have been adopted. 'Supportive care' is defined as care that aims to optimize the comfort, function, and social support of the patients and their families at all stages of the illness. This dimension of care emphasizes the oncologist's role in optimizing the quality-of-life for all patients, including those with potentially curative illness. 'Palliative care' is defined as care that aims to optimize the comfort, function, and social support of the patients and their family when cure is not possible. This dimension of care emphasizes the special needs of patients whose illness is either incurable or unlikely to be cured. Needs include physical and psychological symptom control, education, and optimization of community supports. 'End-of-life-care' is defined as palliative care when death is imminent. Patients who are about to die, and their families, have very special and often intense needs that commonly require individualized and intensive clinical care.

The working group has undertaken a series of initiatives to increase the degree of involvement of European medical oncologists in the provision of palliative and

supportive care. The initiatives to date include an ESMO survey that demonstrated a high level of consensus with respect to the importance of the oncologist's role in the provision of supportive and palliative care to patients with advanced cancer and to dying patients. The responding members overwhelmingly supported the opinion that oncologists should coordinate the care of advanced-cancer and dying patients; that supportive and palliative care should be initiated during the active treatment phase; that medical oncologists should be expert in the management of the physical and psychological symptoms of advanced cancer; and that cancer centers should provide supportive and palliative care as part of the basic basket of services. Sadly, but not unexpectedly, the survey also found that there is often a wide gap between the opinions favored and the services actually delivered. Indeed, the survey's outcome highlighted common deficiencies, particularly in the care of psychological and existential distress, coordination with other clinicians involved, and preparation for end-of-life care.

Through a series of policy statements, ESMO has now formalized the special relationship between medical oncology and palliative care. A draft of a policy statement was presented and ratified in June 2002 at the National Representatives¹ meeting in Lugano, Switzerland. The new policy statements signify formal recognition of the oncologist's ongoing role in the palliative care of patients with incurable cancer and of dying patients. Since the goals of medical oncology extend beyond the reduction of tumor burden and the deferral of death to incorporate a qualitative dimension, there is a need for a continuum in patient care, in which both primary therapies and supportive and palliative interventions are tailored to the patient's clinical circumstances. For most patients, it is the medical oncologist who assumes the role of the physician primarily responsible for the provision and coordination of cancer care. These policy statements, presented below, address: (i) the role of the oncologist in the provision of supportive and palliative care; (ii) supportive and palliative care training for medical oncologists; and (iii) minimum standards for the provision of supportive and palliative care by cancer centers.

Policies of this type are statements of what ought to be. They set an organizational agenda and challenge us to minimize the gulf between present, often suboptimal, realities and the ideal of what we ought to be doing. As individual clinicians, teachers, mentors, program directors, and members of institutions, we must rise to the challenge and urgently adopt the policy of integration of palliative care into standard oncology practice.

Policy 1: The role of the oncologist in the provision of supportive and palliative care

The medical oncologist must be skilled in the supportive and palliative care of patients with cancer, and in end-of-life care. Consequently, specific training in these skills must be a part of the core curriculum of all accredited training programs.

The delivery of supportive and palliative care to cancer patients requires an appropriate medical nursing and paramedical infrastructure to address the special needs of these patients and their families. It is the responsibility of the medical oncologist to assess and evaluate physical and psychological symptoms of patients under their care and to ensure that these problems are adequately addressed.

The delivery of high-quality supportive and palliative care requires cooperation and coordination with physicians from other disciplines (radiotherapy, surgery, rehabilitation, psycho-oncology, pain medicine and anesthesiology, palliative medicine, etc.) as well as with paramedical clinicians (nursing, social work, psychology, physical and occupational therapy, chaplains, and others).

Regarding end-of-life care for cancer patients, ESMO endorses the Core Principles for End-of-Life Care [3]. Care at the end of life should:

- Respect the dignity of both the patient and caregivers;
- Be sensitive to and respectful of the patient's and family's wishes;
- Use the most appropriate measures that are consistent with patient choices;
- Make alleviation of pain and other physical symptoms a high priority;
- Recognize that good care for the dying person requires quality medical care but also entails services that are family- and community-based in order to address – for example – psychological, social, and spiritual/religious problems;
- Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and medical oncology providers);
- Advocate access to therapies that can reasonably be expected to improve the patient's quality-of-life, and ensure that patients who choose alternative or non-traditional treatments are not abandoned;
- Provide access to palliative care and hospice care;
- Respect the patient's right to refuse treatment, as expressed by the patient or an authorized surrogate;
- Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;
- Promote clinical and evidence-based research on providing care at the end of life.

Policy 2: ESMO policy regarding

supportive and palliative care training for medical oncologists

Medical oncologists must be skilled in the supportive and palliative care of patients with advanced cancer. Consequently, specific training in these skills must be a part of the curriculum of all accredited training programs.

Nine core skills must be incorporated:

1) The oncological management of advanced cancer

Medical oncologists must be expert in the appropriate use of antitumor therapies as palliative techniques when cure is no longer possible. This includes specific familiarity with key concepts of patient benefit, quality-of-life and risk/benefit analysis.

2) Communication with patients and family members

The medical oncologist must be skilled in effective and compassionate communication with cancer patients and their families. Specific skills include: explaining diagnosis and treatment options, disclosure of diagnosis, explaining issues relating to prognosis, explaining the potential risks and benefits of treatment options, counseling skills to facilitate effective and informed decision-making, explaining the role of palliative care, and care of distressed family members (fear, anticipatory grief, bereavement care, and the convening of family meetings).

3) The management of complications of cancer

Medical oncologists must be expert in the evaluation and management of the complications of cancer, including: bone metastases, CNS metastases (brain and leptomeningeal metastases), neurological dysfunction (primary, metastatic, paraneoplastic, and iatrogenic), liver metastases and biliary obstruction, malignant effusions (pleural, peritoneal, and pericardial), obstruction of hollow viscera (esophagus, airways, gastric outlet, small and large bowel, ureters), metabolic

consequences of cancer, anorexia and cachexia, and hematological consequences (anemia, neutropenia, thrombocytopenia, clotting diathesis, and sexual dysfunction).

4) Evaluation and management of physical symptoms of cancer and cancer treatment

Medical oncologists must be expert in the evaluation and management of the common physical symptoms of advanced cancer, including: pain, dyspnea and cough, fatigue, nausea and vomiting, constipation, diarrhea, insomnia, and itch.

5) Evaluation and management of psychological and existential symptoms of cancer

Medical oncologists must be familiar with the evaluation and management of the common psychological and existential symptoms of cancer, including: anxiety, depression, delirium, suicidal desire or desire for death, death anxiety, and anticipatory grief.

6) Interdisciplinary care

Medical oncologists must be familiar with the roles of other professions in the care of patients with cancer and with community resources to support the care of these patients.

7) Palliative care research

Medical oncologists must be familiar with research methodologies that are applicable to patients with cancer, including: quality-of-life research, pain measurement and research, measurement of other physical and psychological symptoms (dyspnea, fatigue, nausea and vomiting, depression and anxiety, desire for death), needs evaluation, decision-making research, and palliative care audit.

8) Ethical issues in the management of patients with cancer

Medical oncologists must be familiar with common ethical problems that arise in the management of advanced cancer and with ethical principles that assist in resolving the problems: ethical issues related to disclosure of diagnosis and prognosis; ethical issues in decision-making (paternalism, autonomy, informed consent); the right to adequate relief of physical and psychological symptoms and its implications; ethical issues at the end of life (sedation for refractory symptoms, hydration and nutrition at the end of life, daunorubicin, use of invasive palliative approaches, i.e. nephrostomy or dialysis); forgoing treatment; and issues related to euthanasia and assisted suicide.

9) Preventing burnout

The medical oncologist must be familiar with the symptoms of burnout, the factors that contribute to burnout and strategies to prevent its development.

Different levels of competence are expected for different core skills: 'expert' refers to a high level of academic and practical knowledge; 'skilled' refers to effective clinical competence; and 'familiar' refers to familiarity with core concepts, sufficient for adequately evaluating the patient, initiating basic therapy, and communicating with clinical experts.

At the completion of training, graduates should be expert in the oncological management of advanced cancer, the management of complications of cancer and the evaluation and management of physical symptoms of cancer and cancer treatment.

They should be skilled in communication with patients and family members, and they should be familiar with the evaluation and management of psychological and existential symptoms of cancer, the interdisciplinary care of patients who have

advanced cancer, palliative care research, ethical issues in the management of patients with cancer, and prevention of burnout.

Policy 3: ESMO policy regarding minimum standards for the provision of supportive and palliative care by cancer centers

Since most cancer patients receive their cancer care in dedicated clinics or hospitals, it is imperative that these facilities provide an adequate supportive and palliative care infrastructure as part of the overall service. Key tasks of supportive and palliative care provision in the cancer center include the screening of cancer patients to identify those who have specific needs, and the provision of real-time supportive and palliative care interventions as part of routine cancer care.

Minimum requirements of palliative care in the cancer center include:

- Cancer patients (especially those who have advanced cancer) receiving active therapy in cancer centers should routinely be assessed for the presence and severity of physical and psychological symptoms and for the adequacy of social supports.
- When inadequately controlled symptoms are identified, they must be evaluated and treated with the appropriate urgency, depending on the nature and severity of the problem.
- The cancer center must provide skilled emergency care for inadequately relieved physical and psychological symptoms.
- Cancer centers must ensure an ongoing program of palliative and supportive care for patients with advanced cancer who no longer derive any benefit from anti-tumor interventions.
- Cancer centers should incorporate social work and psychological care into routine care.
- When patients require in-patient end-of-life care, the cancer center staff either provides the needed in-patient care or arranges adequate care in an appropriate hospice or palliative care service.

For further information:

chernyn@netvision.net.il

1 Medical Oncology and Palliative Medicine Service, Department of Oncology, Shaare Zedek

Medical Center, Jerusalem, Israel;

2 Sheba Medical Center, Tel Aviv University Medical School, Israel;

3 Methaxa Cancer Center, Piraeus, Greece;

4 M. Tonato, Policlinico Divisione Oncologia Medica, Perugia, Italy; M. Maltoni, Pierantoni Hospital

Department of Medical Oncology, Forlì, Italy; K. Winand Lange, Johanniter-Krankenhaus

Rheinhausen, Duisburg, Germany; H. Kappauf, Institut für Medizinische Onkologie, Nürnberg,

Germany; M. Kloke, Universitätsklinikum Essen, Essen, Germany; A.-C. Grigorescu, Oncologic

Institute of Bucharest, Bucharest, Romania; S. Tjulandin, Cancer Research Center, Moscow, Russia;

V. Bryuzgin, Cancer Research Center, Moscow, Russia; P. Siedlecki, M. Skledowska-Curie Institute

Cancer Center, Warsaw, Poland; K. Holli, University Hospital Department of Oncology, Tampere,

Finland; D. Schrijvers, Middelheim Hospital in Belgium, Antwerp, Belgium; Ö. Özyilkan, Baskent University Faculty of Medicine, Ankara, Turkey; M. Chasen, R. Eek Sandton Oncology Centre, Pretoria, South Africa; M. Wagnerova, University Teaching Hospital, Kosice, Slovak Republic; J. Szanto, Debrecen Medical University, Debrecen, Hungary; and J. Oliveira, Instituto Portugues de Oncologia, Lisboa Codex, Portugal

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