



ESMO's new direction in supportive and palliative care

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Cancer patients with advanced and incurable disease are as much the responsibility of oncologists as those whose disease is potentially curable. This is the message that is emanating loud and clear from The European Society of Medical Oncologists. In Europe, as in the United States, the major professional bodies have declared that oncologists must take responsibility for and be skilled in the care of their patients who cannot be cured. Furthermore, they have asserted that this responsibility extends beyond the point when anti-cancer treatments may no longer be helpful.

As declared in the editorial heralding the ESMO policy statements: "the division of cancer care into an initial trial primary antitumor therapies followed by hospice or palliative care for patients who have progressive disease is anachronistic". 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 need for a continuum in patient care in which both primary therapies and supportive and palliative interventions are tailored to the clinical circumstances of the patient." (1).

The care of patients with advanced and incurable cancer occupies a major part of most oncologists practice (2). This comes as no surprise given that the cure rate for cancer remains less than 50% and that cancer continues to account for over 25% of all adult deaths (3). ESMO recognizes that a great many patients will not be cured, and that for them the issues regarding the quality of their remaining time is critical, irrespective of the duration of survival. It has been almost five years since ESMO, at the suggestion of the then national representative from Israel (Prof Raphael Catane), established a special working group to address the relationship between medical oncology and supportive/palliative care. No one at the time would have anticipated the impact of this initiative. Since then, ESMO has clarified and ratified definitions of supportive and palliative care (Table 1), defined the responsibilities of the oncologist in the provision of palliative and supportive care (Table 2), outlined training requirements for oncologists in relation to these aspect of patient care (Table 3), and established minimal standards for cancer centers (Table 4) (1).

These policies are binding upon all individual members, associated organizations and bodies, and affiliated centers.

Table 1. ESMO definitions

Supportive care: care that aims to optimize, the comfort, function and social support of the patient and their family at all stages of the illness.
Palliative care: care that aims to optimize, the comfort, function and social support of the patient and their family when cure is not possible.
End of life care: palliative care when death is imminent

Adapted from: Cherny NI, Catane R, Kosmidis P. ESMO takes a stand on supportive and palliative care. *Ann Oncol* 2003;14(9):1335-7 (1)

Table 2. ESMO policy regarding the role of the oncologist in the provision of supportive and palliative care

1. The medical oncologist must be skilled in the supportive and palliative care of patients with cancer and in end-of-life care.
2. The oncologist must address the need for an appropriate medical nursing and paramedical infrastructure to address the special needs of these patients and their families.
3. 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.
4. The delivery of high quality supportive and palliative care requires co-operation and coordination with physicians of other disciplines (including radiotherapy, surgery, rehabilitation, psych-oncology, pain medicine and anesthesiology, palliative medicine etc) as well as with paramedical clinicians (including nursing, social work, psychology, physical and occupational therapy, chaplains and others).
 - In the care of dying patients the medical oncologist must:
 - Respect for the dignity of both 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 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 which are reasonably expected to improve the patient's quality of life and ensure that patients who choose alternative and nontraditional treatments not be 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.

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Table 3. ESMO's 9 core skills for supportive and palliative care training for medical oncologists

1	The oncologic management of advanced cancer	Medical oncologists must be expert in the appropriate use of anti tumor 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	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 risk and benefits of treatment options; Counseling skills to facilitate effective, informed decision making; Explaining the role of palliative care; The care of distressed family members: fear, anticipatory grief, bereavement care; 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; Hematologic consequences: anemia, neutropenia, thrombocytopenia, clotting diathesis; 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; 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; Suicidality and desire for death; Death anxiety; 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 oncologist 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; Palliative Care audit
8	Ethical issues in the management of patients with cancer	Medical oncologist must be familiar with common ethical problems that arise in the management of advanced cancer and ethical principles that assist in their resolution: 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; Consent: informed, uninformed; Ethical issues at the end of life: sedation for refractory symptoms, hydration and nutrition at the end of life, DNR, use of invasive palliative approaches; Foregoing treatment; Euthanasia, assisted suicide
9	Preventing burnout	Medical oncologist must be familiar with the symptoms of burnout, the factors that contribute to burnout and strategies to prevent its development.

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Policy statements are not enough. ESMO knew it had a problem in the actual delivery of palliative care by many oncologists, and it wanted to know exactly what and how widespread those problems were. To this end, the organization surveyed its membership to evaluate the attitudes and actual practices of ESMO affiliated oncologists. This survey (2), the most comprehensive of its kind, found that as a whole ESMO oncologists had very favorable and appropriate attitudes with regards to their responsibilities in the provision of supportive and palliative care. Overwhelmingly, they saw it as their responsibility and they expressed commitment to continuity of care and to the provision of high quality end of life care in cooperation with other health care professionals. On the downside, however, the survey found

Table 4. Minimal standards for the provision of supportive and palliative care by cancer centers

1. Cancer patients receiving active therapy in cancer centers, especially those with advanced cancer, should be routinely assessed regarding the presence and severity of physical and psychological symptoms and the adequacy of social supports
2. 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).
3. Cancer center must provide skilled emergency care of inadequately relieved physical and psychological symptoms.
4. Cancer centers must ensure an ongoing program of palliative and supportive care for patients with advanced cancer who are no longer benefited by anti-tumor interventions.
5. Cancer centers should incorporate social work and psychological care as part of routine care.
6. When patients require inpatient end of life care, the cancer center staff either provide the needed inpatient care or arrange adequate care in an appropriate hospice or palliative care service.

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that there was a substantial gap between expressed beliefs and actual practice. For example, whereas, 88.4% of respondents agreed that medical oncologists should coordinate the care of cancer patients at all stages of disease including end of life care, in actual practice only 43% of respondents reported that they commonly coordinate the care of cancer patients at all stages of disease including end of life care, less than 50% collaborate commonly with any supportive/palliative care clinician (including social workers), only 39% commonly coordinate meetings with the family of dying patients, and only 11.8% commonly manage delirium (despite the high prevalence of this problem among patients with far advanced cancer). Interestingly, whereas 60.4% of respondents reported that they were expert in the management of the physical and psychological symptoms of advanced cancer, only 37.0% said most oncologists they knew were expert in the management of the physical and psychological symptoms of advanced cancer.

Importantly, the survey highlighted that these was a close relationship between negative attitudes toward palliative care, lack of personal care delivery, lack of consultation with palliative care colleagues from other disciplines, and "catastrophic fear" of burnout from involvement in end of life care. Those clinicians with the greatest fear did the least, had negative attitudes, and not only did they not provide care they did not refer or consult with appropriate clinicians expert in end of life care. ESMO hopes that its new education policy will better prepare oncologists for these aspects of care.

ESMO recognizes that oncologists work in a clinical context; some in private clinics, but most in hospitals and cancer centers. It is incumbent upon cancer clinics and hospitals to provide the infrastructure and supports needed to ensure adequate supportive and palliative care. All patients with advanced, potentially life threatening illness must have access to a social worker to help evaluate emotional and social coping and to assist in coordinating care. Many patients will need ambulatory or inpatient care for management of physical or psychological symptoms and, some will need access to inpatient end-of-life care. These aspects of care will need interdisciplinary cooperation, which often incorporate palliative care or hospice specialists. Not all patients needing inpatient end of life care can or will be care for in oncology departments, but it is incumbent upon the treating oncologist to ensure that this aspect of care be carried out with sensitivity and expertise. Dying patients must not be abandoned or be allowed to "fall between the cracks of the system". Consequently, the third of its policy statements describes minimal standards for supportive and palliative care to be provided by cancer centers (Table 4). This policy applies not only to major comprehensive cancer centers, but to private clinics and hospital based services also.

The steps taken thus far are a beginning. ESMO recognizes that it is trying to change a culture of care. Making palliative care a normative part of oncology practice, no less than the

administration of chemotherapy or antiemetic is going to take time, energy, initiative and reinforcement. ESMO regards the incorporation of supportive and palliative care into routine cancer care as an expression of "good clinical practice". For oncologists, neglecting the issue is not an option and, indeed, it verges on malpractice.

Along with the policy statements, ESMO has undertaken a series of educational and incentive programs to further promote this important endeavor. Among the most prominent of the initiatives is an incentive program to give special recognition to centers that meet an especially high standard in the integration of oncology and palliative medicine. Already more than 20 centers have applied for this recognition.

This is a new direction for ESMO but it is a direction that the organization views as critical to the development of our specialty as both a humane and responsible initiative.

REFERENCES

1. Cherny NI, Catane R, Kosmidis P. ESMO takes a stand on supportive and palliative care. *Ann Oncol* 2003;14(9):1335-7.
2. Cherny NI, Catane R. Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: report on a survey by the European Society of Medical Oncology Taskforce on Palliative and Supportive Care. *Cancer* 2003;98(11):2502-10.
3. Jemal A, Thomas A, Murray T, Thun M. Cancer statistics, 2002. *CA Cancer J Clin* 2002;52(1):23-47.