Oncology has come a long way in addressing patients’ quality of life, together with developing surgical, radio-oncological and medical anticancer therapies. However, the multiple and varying needs of patients are still not being met adequately as part of routine cancer care. Supportive and palliative care interventions should be integrated, dynamic, personalised and based on best evidence. They should start at the time of diagnosis and continue through to end-of-life or survivorship. ESMO is committed to excellence in all aspects of oncological care during the continuum of the cancer experience. Following the 2003 ESMO stand on supportive and palliative care (Cherny N, Catane R, Kosmidis P. ESMO takes a stand on supportive and palliative care. Ann Oncol 2003; 14(9): 1335–1337), this position paper highlights the evolving and growing gap between the needs of cancer patients and the actual provision of care. The concept of patient-centred cancer care is presented along with key requisites and areas for further work.

Key words: position paper, ESMO, supportive care, palliative care, patient-centred care, multidisciplinarity

Introduction

Based on GLOBOCAN estimates, about 14.1 million new cancer cases and 8.2 million cancer-related deaths occurred in 2012 worldwide [1]. Due to the accelerated pace of progress in diagnostics and treatments, more patients are now cured or live longer with metastatic disease.

Nevertheless, a cancer diagnosis, the disease itself and the sequelae of anticancer treatment are major stress factors for patients. Over the last decade clinicians have accepted that, while survival and disease-free survival are both fundamental factors, overall quality of life (QoL) is also crucial for patients. The latter evidenced by the increasing use of QoL as high-level end points in clinical trials of anticancer therapies [2–4]. Depending on diagnosis, cancer patients will receive different types and intensities of tumour-directed treatment (i.e. antineoplastic therapy, radiotherapy and/or surgery). Along with antitumour treatment, most patients need help to prevent and alleviate side-effects and toxicities, and to cope with the disease itself. Furthermore—at any stage of the cancer pathway—physical, psychological, social, existential and spiritual support and rehabilitation, are often needed. For optimal management, patients must be fully involved in the decision-making process.

Building on previous ESMO policy statements and guidelines, and considering the unfulfilled needs of cancer patients [5], this position paper advocates for patient-centred care (including supportive and palliative care) to be integrated by a multidisciplinary team (MDT) to anticancer treatment, from the time of diagnosis...
and throughout the continuum of disease, including end-of-life and survivorship care.

ESMO is committed to increasing awareness and education to bring patient-centred care closer to all professionals, to improving collaboration between healthcare providers for the good of patients and to promoting research, so that patient-centred interventions are not only integrated, but also based on the best evidence.

This paper was prepared by parts of the ESMO Faculty Group on Supportive Care and Palliative Care. A meeting coordinated by the ESMO Educational Committee was held in May 2017 to discuss the content and structure of the paper. The draft went through several rounds of review by the group and was approved by both the group and the Educational Committee Chair.

**Supportive and palliative care: all about the patient**

Clinicians have always intended to provide the best care for their patients. However, health systems do not always enable this. Consciously putting patients’ holistic needs at the centre of everything is the cornerstone of supportive and palliative care. This position paper goes beyond the debate about the standard definitions of supportive, palliative and end-of-life care. Much work has already been done in this area [6–8].

Two widely accepted definitions are provided below as examples.

The Multinational Association of Supportive Care in Cancer (MASCC) has proposed the following definition of supportive care: ‘Supportive care in cancer is the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side-effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship and end-of-life care are integral to supportive care’ [9].

The World Health Organisation (WHO) has proposed the following definition for palliative care: ‘Palliative care is an approach that improves the QoL of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death’ [7].

While definitions are important and studies have shown that the word ‘palliative’ may have negative connotations for patients and could even delay their referral or readiness to accept interventions [10], efforts must be focused on alleviating patients’ physical symptoms and psychological concerns, rather than on debating definitions.

The ESMO Supportive and Palliative Care Faculty proposes the use of the term ‘patient-centred care’ [11, 12] to encompass both supportive and palliative care. To offer optimal patient-centred care, institutions should be organised (according to their structure and goals) in a way to make this possible, with the necessary level of professional competence, skills and a collaborative organisation that facilitates care pathways, individualised according to the needs of each patient.

**The patient-centred care approach**

Individual cancer patients will express different physical, psychological, social, existential and spiritual needs at different stages of the disease that will often evolve over time. Therefore, patient-centred care cannot be standardised, even though it is provided through a standard framework. To ensure that patients can voice their needs, oncologists should incorporate detailed and routine physical and psychological assessments allowing for supportive and palliative interventions to be personalised and integrated in the continuum of care. Patient-reported outcomes (PROs) should be highly encouraged as requesting them has shown to be associated with better QoL, fewer hospitalisations and even increased survival compared with usual care [13].

Patient-centred interventions should be routinely discussed and evaluated by the MDT, together with tumour directed treatment, respecting patient preferences and cultural specificities.

**Key patient-centred care interventions**

The MDT caring for patients should be able to address their multiple and varying needs. Table 1 shows some examples of key patient-centred care interventions regarding assessment, monitoring and management strategies.

**Timely patient-centred interventions**

Patient-centred care should be offered during the continuum of illness, from the time of cancer diagnosis through to survivorship or end-of-life. Needs will evolve together with the disease and anticancer treatment, so ongoing and careful holistic evaluation of requirements should be part of every consultation (see section on key interventions above).

For some patients diagnosed at an early stage, the treatment period is relatively short and, after follow-up, they become long-term survivors or are considered cured (Figure 1, the curative phase and survivorship phase). For these patients, rehabilitation, prevention and management of adverse side-effects are most important. Some patients will have one or more comorbidities at the time of their cancer diagnosis that may require intervention before the start of treatment; others may need rehabilitation due to treatment-induced long-term adverse effects. When cancer patients have advanced disease at the time of diagnosis, cure is usually not possible (Figure 1, palliative phase and end-of-life phase) and palliative care should be considered from diagnosis onwards [14].

Recent studies show variable effects of the integration of early supportive/palliative care interventions. A few systematic reviews concluded that early palliative care in patients with advanced cancer significantly [15] or slightly [16, 17] improved patients’ QoL and could decrease symptom intensity, although overall survival was not prolonged. The most recent studies were not included in
Table 1. Key patient-centred care interventions (examples)

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Monitoring and intervention: regular changes in patients’ health status preferably assessed with PROMs or other validated assessment tools</th>
<th>Management of cancer-related symptoms and other needs</th>
<th>Management of anticancer treatment-related toxicities and complications, including prevention</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cancer and anticancer-treatment related symptoms, toxicities, complications</td>
<td>• Adverse events of anticancer treatment, specifically under immunotherapy</td>
<td>• Pain</td>
<td>• Nausea and vomiting</td>
</tr>
<tr>
<td>• Psychological disorders, distress</td>
<td>• Compliance/adherence to oncologic treatments (e.g. oral antineoplastic agents)</td>
<td>• Fatigue</td>
<td>• Anaemia</td>
</tr>
<tr>
<td>• Sleeping problems</td>
<td>• Frequency of unplanned visits and/or unplanned hospitalisation</td>
<td>• Nausea and vomiting</td>
<td>• Febrile neutropenia</td>
</tr>
<tr>
<td>• Spiritual and existential issues</td>
<td>• Special survivors’ needs</td>
<td>• Constipation, diarrhoea</td>
<td>• Fatigue</td>
</tr>
<tr>
<td>• Comorbidities</td>
<td>• Coping mechanisms</td>
<td>• Anorexia, cachexia, early satiety</td>
<td>• Pain</td>
</tr>
<tr>
<td>• Nutritional status</td>
<td>• Understanding of illness, treatment and care options</td>
<td>• Dyspnoea/breathlessness</td>
<td>• Infections</td>
</tr>
<tr>
<td>• Sexuality concerns</td>
<td>• Patient and caregiver information (including help from cultural mediators when needed)</td>
<td>• Hydro electrolytic disorders</td>
<td>• Dermatotoxicity</td>
</tr>
<tr>
<td>• Prognosis and coping with cancer disease</td>
<td>• Treatment decision-making</td>
<td>• Prevention of skeletal related events in patients with bone metastases</td>
<td>• Neurotoxicity</td>
</tr>
<tr>
<td>• Family and/or caregiver issues</td>
<td>• Advance care planning</td>
<td>• Anxiety</td>
<td>• Immune-related adverse events</td>
</tr>
<tr>
<td>• Socioeconomic issues</td>
<td>• Preparation for end-of-life and dying</td>
<td>• Depression</td>
<td>• Diarrhoea/constipation</td>
</tr>
<tr>
<td>• Other unmet needs</td>
<td>• Family distress and care-giving roles</td>
<td>• Sleeping disorders</td>
<td>• Mucositis</td>
</tr>
<tr>
<td></td>
<td>• Professional support networks</td>
<td>• Evacuative paracentesis</td>
<td>• Renal impairment,</td>
</tr>
<tr>
<td></td>
<td>• Loss of autonomy</td>
<td>• Endurance, resistance and balance training</td>
<td>• Cardiotoxicity</td>
</tr>
<tr>
<td></td>
<td>• Distress</td>
<td>• Support in understanding the disease itself as well as the diagnosis, treatment options and prognosis</td>
<td>• Problems with sexuality</td>
</tr>
<tr>
<td></td>
<td>• Existential, spiritual and religious needs</td>
<td>• Supporting decisional processes of patient and family</td>
<td>• Endocrine disorders</td>
</tr>
<tr>
<td></td>
<td>• Other monitoring and intervention issues</td>
<td>• Organising and coordinating community support networks</td>
<td>• Arthralgia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Coping with life limiting expectancies</td>
<td>• Prevention of CTIBL</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Other management issues</td>
<td>• Prevention of infertility</td>
</tr>
</tbody>
</table>

PROMs, patient-reported outcome measures; CTIBL, cancer treatment-induced bone loss.

Figure 1. Schematic diagram of the cancer pathway. *Rehabilitation may also apply in the palliative setting.

these reviews. These results include negative studies [18]. The overall impression is that early integration of palliative care is beneficial to patients with advanced cancer at the time of diagnosis [19].

Recently, dedicated outpatient supportive care teams focusing on prevention and management of anticancer treatment toxicities have been developed [20, 21]. Data from Italian [22] and French [23] dedicated supportive care units show a reduction of unplanned hospitalisations of cancer patients undergoing treatment [24] and for those requiring blood transfusion [25], allowing for cost-effective management of symptoms and anticancer treatment-related toxicity in an ambulatory setting [26]. However, current literature is still scarce on supportive care units, so more randomised clinical trial (RCTs) should be encouraged in this field.

Survivorship, pre- and rehabilitation

Although patient-centred care is needed throughout the disease, some phases deserve specific attention and more research. For example, due to the improvement of anticancer therapy efficacy, millions of patients today survive and live with a history of cancer. For them, ESMO encourages oncologists, in partnership with MDTs, to develop programmes of:

• Prehabilitation (at the time of diagnosis or relapse) to reduce frailty and prepare patients to receive adequate treatment. Prehabilitation may also reduce post-treatment disorders [27, 28].
• Rehabilitation to reduce acute and chronic disabilities due to anti-neoplastic treatments. The objective is to help patients become and remain independent and productive members of society, or to cope better with remaining limitations [29]. Rehabilitation, however, can also be applied in palliative situations.
• Survivor care plans, to support patients in recovering ‘well-being’ in their personal, professional and social lives, may reduce the risk of recurrence and help manage chronic disease, but further research is needed on how to apply them in clinical practice [30–32].

End-of-life care

Special attention should be paid to patients and their caregivers when life prolonging treatment comes to an end. In order to help them cope with this transition, advanced care planning [33] as a tool should be used early in the course of palliative chemo and radiotherapy. Near the end-of-life [34], particularly during the last days, these plans need to be adapted to patients and family members’ individual needs, based on an open communication about the natural course of the disease and the dying process [35].

‘Advanced directives’ should be discussed when appropriate, at any time in the disease trajectory, allowing patients to spell out their wishes about end-of-life care ahead of time. Discussing the patient’s status and prognosis can be challenging for professionals, therefore communication skills are essential.

Oncologists should be prepared to respond to emotions and to discuss the possible outcomes of cancer, including death. Professionals should be able to understand what matters most to patients and their families, to explain options simply and clearly, to help patients anticipate and plan in a way that is respectful of their wishes. This includes respecting the patient’s right to refuse treatment.

The UK’s National Institute for Health and Care Excellence (NICE) offers useful guidelines for care, as well as for pharmacological and non-pharmacological interventions, in the last days of life [34], although the UK health care system including hospices may not be transferable to other countries.

Multidisciplinary teams

The list of professionals that compose an MDT caring for patients includes several specialties. In summary, there should be medical oncologists, palliative medicine specialists, nurses, tumour origin specialists, radiation oncologists, surgeons, pharmacists, allied healthcare professionals, clerics and volunteers involved. A more extensive list of professions that may be included in the MDT is provided in the online supplement (see supplementary Table S1, available at Annals of Oncology online). Of course, not all patients will need the involvement of all these professionals.

The composition of the MDT, as well as tasks and responsibilities, will vary according to patient needs, resources and national settings. Nevertheless, the team should encompass medical and non-medical professionals that can take care of a wide variety of physical, psychological, social and existential needs.

If, due to financial or organisational limitations, the cancer centre does not have the necessary staff in-house to cater to all patient needs, patients should be referred to other centres or to individual, trained, professionals (such as physiotherapists or psychologists) where they have access to necessary interventions. It is important that the medical oncologist in charge of treatment and care is also responsible for coordinating these interventions and regularly evaluates the efficacy of patient-centred care [23].

Integrating healthcare resources

ESMO has a long-term commitment to advance the integration of supportive and palliative care in oncology and to excellence in all aspects of oncological care.

Integration is needed to coordinate care processes, including establishing what health care resources are needed: ‘the correct competence in the right place at the right time’. The concept of integration of palliative care into oncology has received substantial attention recently although there is still no consensus on a definition of ‘integration’. In a recent article, Hui and Bruera [36] summarized 38 aspects of integration based on a systematic review, which were classified under 5 categories (clinical structure, clinical process, education, research and administration). Subsequently, an international Delphi panel highlighted 13 criteria as major indicators of integration which may be useful for benchmarking palliative care access across healthcare systems [37].

In order to improve the current situation, ESMO is committed to expanding cooperation with other professional medical associations and organisations worldwide (such as the European Association of Palliative Care (EAPC), the Multinational Association of Supportive Care in Cancer (MASCC), etc.) and to encourage and sustain supportive and palliative care development through its ‘ESMO Designated Centre of Integrated Oncology and Palliative Care’ programme [38, 39].

Adequate patient-centred care should be provided as part of the global service of every hospital or clinic treating cancer patients. Integrating patient-centred services is the best way to ensure that they will be widely available and acceptable to professionals and patients alike. The Eligibility Criteria Checklist of the ESMO Designated Centre of Integrated Oncology and Palliative Care programme can be seen on the ESMO website [40].

Resources being limited, not all oncology centres will have an extended MDT (and not all patients will need support) but, as a minimum, regular routine patient assessment of physical and psycho-social needs should be offered, as well as provision of interventions, whether in-house or by referral to medical or non-medical professionals.

Need for specific training in patient-centred care

ESMO is committed to specialised education supporting oncologists in a fast-changing professional environment. The society aims to help oncologists gain in-depth, disease-specific knowledge as well as learning how to collaborate effectively with other specialists in an integrated, multi-professional setting.

Medical oncologists should be trained in the supportive and palliative care of patients, including basic knowledge about physical, psychological, social and spiritual aspects of cancer, as set out in the ESMO/ASCO Recommendations for a Global Curriculum
in Medical Oncology (see Table 2) [41]. As such a structured rotation in supportive and palliative care for oncology trainees would be a helpful approach. Furthermore, as stated in 2003, ESMO considers oncologists ‘should be familiar with the roles of other professionals in the care of patients with cancer and with community resources to support the care of these patients’. If specialist patient-centred care is required, oncologists should be able to identify which appropriate professional the patient should be referred to.

National Societies should also promote continuing medical education (CME) in the basics of patient-centred care, to ensure professionals learn about new developments in the field.

Requirements of the ESMO/ASCO Curriculum are addressed in the following sections:

- Complications/toxicities of anticancer treatment.
- Supportive care measures.
- Palliative care.
- End-of-life care.

The objectives encompassed are shown in Table 2.

### ESMO resources for integrated patient-centred care education

ESMO already offers a wide array of educational programmes and tools to oncologists in the domain of patient-centred care (see Table 3).

### Research needs and resources in supportive and palliative care

Despite growing awareness of the need to develop patient-centred care and recent progress in the field, more and better scientific evidence, tailored to individual and fluctuating patient needs is required so that effective interventions can be proposed to cancer patients at each stage of their illness.

Prospective, well-designed and preferably, intervention studies are needed to evaluate the impact of palliative and supportive interventions on outcomes and QoL. Even in pain management the level of evidence in existing guidelines is low [42–44]. In this area, the ESMO-led Global Opioid Policy Initiative (Gopi) [45] seeks to drive necessary policy reform to improve severe cancer pain management and unnecessary suffering. It calls for authorities to guarantee the availability and accessibility of effective and safe pain killing treatments.

ESMO is willing to promote more research fellowships in supportive and palliative care. Research in patient-centred care should be the focus of original investigation. For anticancer treatment trials, PROs should be used together with traditional tumour-oriented outcomes. It is not enough to include QoL measures in cancer clinical trials as secondary or tertiary outcomes.

Often, only research validated by RCTs is considered acceptable. Nevertheless, there are methodological and ethical issues [46] linked to RCTs in palliative and end-of-life care (i.e. concerns about informed consent and the vulnerability of patients). However, recent RCTs in this setting and embedded in qualitative work showed that patients with advanced cancer benefit from participation in symptom control trials [47, 48].

Other options include well-designed observational studies and cross-sectional surveys [49]. More research is needed, for example, on short- and long-term side-effects of new therapeutic interventions [50]; new supportive care agents; integrating new technologies such as a web-based programmes and apps for self-monitoring and reporting symptoms; congruent outcome assessments on symptoms and side-effects (health care assessment versus PROs); nutrition, physical activity, QoL; social factors such as family issues, social support, work, financial toxicity; care giver attitudes and practices; rehabilitation and survivor care; identifying organisational, economic and other incentives for the provision of integrated and affordable patient-centred care.

ESMO calls for more research to be carried out in this area in order to create the evidence needed to improve patient-centred care. Furthermore, a pragmatic approach to cancer research is needed where patient-centred care trials are concurrent with cancer therapy trials.

### Table 2. Requirements of the ESMO/ASCO Curriculum

- To be able to assess, diagnose and treat patients with complications/toxicities of anticancer therapies
- To be able to understand, evaluate and provide supportive care to patients with cancer, including management of symptoms from the cancer and side-effects of therapy from the time of diagnosis until death or until rehabilitation and survivorship issues have been successfully managed
- To know the indications for the different supportive treatments and their limitations and side-effects
- To be aware of the importance of a multidisciplinary approach
- To be able to screen for, assess, prevent and manage symptoms of patients with cancer such as pain, fatigue, anorexia, anxiety, depression, breathlessness and nausea
- To communicate effectively with patients and families about illness understanding and coping with it, prognosis, difficult decisions, end-of-life and its preparation
- To recognise the role of cancer rehabilitation, including physical therapy and nutrition
- To recognise the importance of culturally competent, multidisciplinary care including families
- To understand how to integrate palliative interventions in routine multidisciplinary cancer care
- To recognise the difference between burnout, compassion fatigue and depression
- To recognise the unique aspects of end-of-life care, such as decision-making processes, symptom management, involvement of family members and spiritual aspects
- To understand how to recognise pseudo-refractory symptoms and when to refer to specialist palliative care teams for management of refractory symptoms
- To understand how to maintain patients’ cognition until close to death with good symptom control
- To be able to assess, treat and counsel patients who are approaching end-of-life
- To incorporate the family and beloved ones into goal planning
- The curriculum also defines the required skills in dealing with the psychosocial aspects of cancer, geriatric oncology, communication, patient education and survivorship.
Table 3. ESMO resources for integrated patient-centred care education

- E-learning modules on supportive and palliative care
- ESMO Palliative Care Fellowships: ESMO provides two palliative care fellowships allowing recipients observation or research at one of the ESMO Designated Centres
- ESMO Clinical Practice Guidelines: including guidelines on supportive care and palliative care.
- ESMO Patient Guides: include, e.g. how to deal with side-effects
- ESMO Handbooks for physicians
- ESMO Academy: includes an overview of standards of care and future perspective in supportive care
- ESMO Preceptorships in supportive care and palliative care
- Oncology Pro Webcasts and Slides, Scientific Meeting Reports: (using search function) http://oncologypro.esmo.org/Slide-Resources
- ESMO Congress track on supportive care and palliative care
- ESMO collaboration with other entities with interest in supportive care and palliative care (e.g. MASCC, EAPC, ESO)
- Other resources on the ESMO website: http://www.esmo.org/Topics/Palliative-and-supportive-care

Future/vision

ESMO is committed to ensuring that patient-centred care is widely understood and integrated into health systems at all levels throughout the disease; that oncologists have the necessary knowledge and skills (competences) and that it is underpinned by a high level of evidence. Therefore, ESMO will advocate for

- increased awareness;
- increased research;
- increases education; and
- increased resources to be dedicated to supportive and palliative care.

ESMO appeals to health authorities in Europe and beyond to ensure that cancer patients have equal access to the best possible patient-centred cancer care that resources allow. This is a medical and ethical imperative.

Discussion

Conclusion

Recent studies show variable effects of the integration of early supportive and palliative care interventions for cancer patients and also emphasise their importance. The diverse outcomes may be partly explained by methodological challenges, i.e. different interventions, outcomes and patient populations applied in published RCTs. Manifestly, more research is needed in patient-centred care.

Together with anticancer therapies, medical oncology should encompass patient-centred care by providing supportive and palliative interventions at all stages of the disease, from the time of diagnosis. The oncologist’s role is not only to deliver the best quality anticancer treatment, but also to consider the impact of the disease and treatment on each patient’s life. Oncologists should be responsible for including and collaborating with health care providers with other competences in outpatient and inpatient clinics in order to alleviate patients’ distress. Since only individual patient needs can determine what support is required at each stage of the disease, it is challenging to define models and standards for best patient-centred care, nevertheless, interventions should be based on the best available evidence.

Further research is needed to ensure that palliative and supportive interventions are evidence based and PROs should be highly encouraged. CME is also essential for oncologists to acquire and update the necessary skills to evaluate patients’ specific needs and provide the best care.

ESMO is committed to ensuring that supportive and palliative care is widely understood, integrated into health systems at all levels and underpinned by evidence.

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