

Integration of Supportive and Palliative Care into Oncology

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Introduction

The goal of integration of supportive and palliative care with oncology is to unite two treatment aims: optimal treatment of the tumour – ‘the tumour-directed approach’ – and optimal treatment of the patient who has the tumour – ‘the patient-directed approach’. There is now a growing body of evidence that integration of these two modes of care will provide the optimum patient-centred care. It benefits patients in terms of improved symptom relief, quality of life (QoL), coping, social functioning and also survival. It is time to stop debating *if* integration should be sought and to focus on *how* best to accomplish integration of supportive and palliative care with oncology. All oncologists should strive to implement this new organisation into every individual patient care pathway.

The European Society for Medical Oncology (ESMO) position paper on supportive and palliative care states that, besides anticancer treatments, most cancer patients need help to prevent and alleviate side effects related to such treatment, and to cope with symptoms and needs related to the disease itself. Most patients wish to live as long as possible but

also as well as possible. Physical, psychological, social, existential and spiritual support is therefore needed at every stage of the cancer pathway and not only if the cancer is incurable.

In a patient-centred care approach, any intervention is introduced both at the appropriate time and according to the patient's needs. To facilitate integration, steps must be taken in several areas, as described below. One major challenge is how to systematically implement supportive and palliative care in routine oncology care. In this regard, the multidisciplinary team (MDT) plays a vital role.

What Do We Mean by Integration?

The term 'early integration' facilitates a departure from the common belief that palliative care is only about end-of-life care or only to be provided when anticancer treatment is no longer an option. However, palliative care should not be dichotomised as 'early' or 'late' – its introduction must be timely and needs-based. Integration in healthcare can be seen as a process designed to overcome the various barriers obstructing delivery of optimal care. These barriers may exist on multiple levels – organisational, financial, professional and/or personal. In cancer treatment, many medical professions are involved, and coordination of timely and appropriate interventions is critical for the optimal treatment outcome. This patient-centred care (including both supportive and palliative care) should be integrated using a multidisciplinary approach for discussions about the best possible treatment for the individual patient throughout the continuum of care – from primary diagnosis to end-of-life care. The patient-centred focus is just as important for patients who are at follow-up after curative treatment. The benefits of coordinating medical specialists in MDTs coming from radiology, pathology, surgery, medical oncology and radiotherapy are no longer questioned.

Integration of anticancer- and patient-directed interventions are proposed as an effort to bridge the gap between oncology and palliative and supportive care. In the presence of metastatic disease, surgery, anticancer agents and radiotherapy are, with some exceptions, delivered with the goal to prolong life and/or to treat symptoms. It may be called palliative

treatment by oncologists, but the majority of people associate palliative care with end-of-life care. Therefore, ‘supportive care’ has been suggested by some experts as a term for any patient-directed measures taken to optimise patient care in earlier phases of the disease, in an effort to lower the threshold for referral, both for oncologists and patients. While definitions are important but also arguable, efforts must be focused on alleviating patients’ physical, psychological, social and existential concerns in all stages of disease, from survivorship to end of life.

New developments in anticancer treatments have prolonged life expectancy for many patients, redefining cancer as a chronic illness. This implies that living with cancer rather than dying from cancer has become a more frequent challenge in oncology care. Living with cancer is a new dimension and challenge for most patients and their caregivers. As mentioned earlier, ‘to live as long and as well as possible’ is the ambitious goal for most patients. It means that healthcare can contribute somewhat, but the lives are lived by each person in their home environment. A balance should be reached between our effort to prolong life, relieve symptoms, improve functions and support patients and their caregivers to live their lives.

How to guide and support the optimal life for patients and caregivers is a ‘complex intervention’ that requires the competence of different healthcare providers. This benefit should be made visible, understandable and balanced for each individual. As mentioned earlier, an MDT approach is needed, therefore supportive and palliative care is always teamwork. The team must also be balanced with the right contribution from the oncologists, and the patients and their caregivers should be considered as members of the MDTs.

Clinical resources, both community-based and in hospitals, are limited. This must be reflected to ensure a level of care appropriate to the complexity of indicated interventions. Structured systematic cooperation between different specialities and between different levels of care may ensure continuity of care when shifting between hospital departments and between hospital-based and community-based settings. Early referrals to palliative care consultations may be obstructed by limited

palliative resources. Different levels of palliative care based on complexity must therefore be outlined, where hospital and primary care/family medicine specialists also work together. Most patients wish to remain at home as much as possible and for as long as possible, and (some) will die at home. In the home environment, families can live and act differently than in most institutions. Well-functioning, community-based care is crucial to achieve this. If the conditions of the patient worsen and specialist care is needed, early access will facilitate better home care and patient care in general. A dynamic organisation is needed where primary care/family medicine specialists and homecare nurses collaborate in an integrated way with specialist oncological and palliative care.

Randomised studies on integration of oncology and palliative care in various cancers were summarised in the 2018 *Lancet Oncology* Commission article (Kaasa et al). Although different designs and endpoints were used, the studies consistently found that integrated care improved survival and symptom control, and led to less anxiety and depression, reduced use of futile chemotherapy at the end of life, and improved family satisfaction, QoL and use of healthcare resources. So, how can we achieve integration?

To facilitate integration, steps must be taken in several areas, including, but not limited to, the following: organisational infrastructures, education, communication skills, systematic assessments of patients' symptoms and needs (including systematic follow-up of the palliative care interventions implemented in response to the assessment) and research.

Organisational Infrastructures

Healthcare services are often organised in 'silos' – administratively, financially, professionally and culturally (Figure 1).

In integrated care, different specialists can provide their services regardless of these silos. Standardised care pathways are one methodology that may facilitate integrated care. In standardised care pathways, the patient course is planned individually based upon a common template. Interactions and critical events may be depicted. Standardised care pathways represent

a means to overcome dependency on the individual physician's practice for referral or intervention. However, standardised care pathways may also become a barrier to integration if they are perceived to limit the physician's evaluations and adjustments.

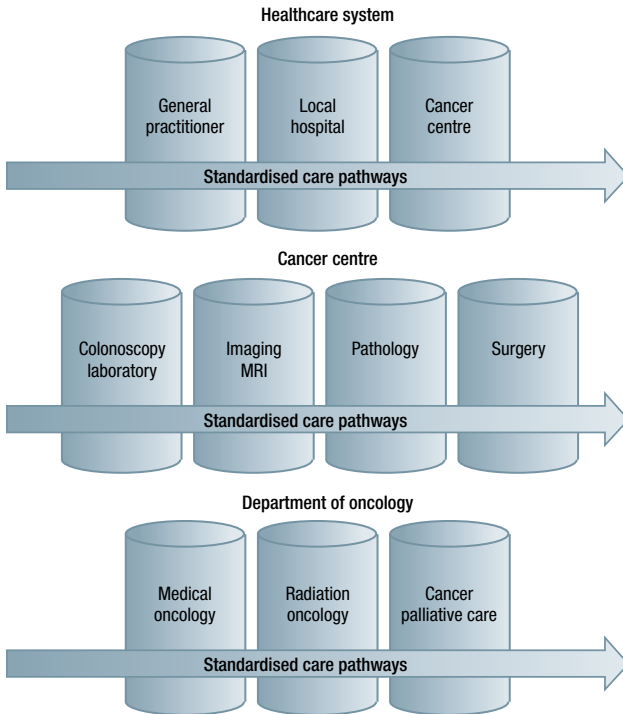


Figure 1 Healthcare includes silos at different levels.

From: Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. *Lancet Oncol* 2018; 19: e588-e653.

Abbreviation: MRI, magnetic resonance imaging.

Co-localisation of services facilitates contact and referral/communication between departments and individuals. Defining which services can be offered as out-patient and which must be in-patient can reduce hospitalisation,

and technology for communication through electronic patient records, or other low-threshold mechanisms for contact between different levels of care (i.e. primary care, hospitals, nursing homes), should be established.

MDTs are organisational structures that coordinate healthcare by bringing together the many specialists involved, improving the quality of the provided care. The composition of MDTs in oncology often varies according to primary cancer type and the situation of the individual patient. Typically, oncology MDT representatives are surgeons, medical and radiation oncologists, radiologists and pathologists; it is uncommon to include palliative care specialists. For a patient-centred approach, palliative care specialists should be included in oncology MDTs. Also, palliative care MDTs should be implemented, further breaking down organisational silos by inviting relevant specialists from the oncology MDTs in addition to other pivotal professions in palliative care, such as physiotherapists, social workers, psychologists, occupational therapists, dieticians and chaplains. Potentially controversial, the patients and their caregivers could also be considered as members of the MDTs. Referral to palliative care MDTs should be based on predefined unacceptable symptom levels from systematic assessments, but appropriate time points for referral should also be defined in the standardised care pathways.

Education

As a rough rule, oncologists have limited postgraduate education in palliative care, and palliative care specialists (who may have postgraduate training varying from country to country) are not consistently required to have oncology training. As a consequence, misconceptions and differences in opinions as to what is defined as appropriate care for the individual patient may impede patient-centred care. Similarly, lack of knowledge and insight into oncology (the tumour-directed treatment) among palliative care specialists and lack of understanding of palliative and supportive care among oncologists may hinder optimal collaboration. We propose that rotations to palliative care units or teams should be compulsory during oncology training, and that oncology rotations should be compulsory during palliative care training. Doctors trained in both oncology and palliative care (palliative oncologists) may serve as

facilitators for optimal integrated care, advocating supportive and palliative care for their oncology colleagues and *vice versa*. Continued medical education in ‘palliative/supportive oncology’ – or indeed patient-centred care – for both specialties should be encouraged. Research in palliation provides oncologists with the opportunity of ‘evidence-based’ best practice and the cooperation between oncologists and palliative care specialists in common research projects should also be encouraged. An international common curriculum in palliative care training, describing mandatory learning goals in essential features of palliative care, should be developed. Such a curriculum could include compulsory rotations in oncology.

Communication Skills

Communication is essential for all clinicians and even more so for oncologists, who are often confronted with breaking bad news during consultations. Continuous training in communication skills must be provided. Appropriate communication skills promote patient-centred care, prognostic awareness and also lower a physician’s risk of burnout. In addition to breaking bad news, oncologists provide information on prognosis and treatment alternatives to the patient and their caregivers. Patients are expected to be actively involved in the decisions about their anticancer treatment (tumour-centred) and planning of care, how to optimise QoL, etc. (patient-centred care). This process of shared decision-making may often be conducted in collaboration between the oncologist, palliative care specialist, home care personnel and the family practitioner.

Systematic Assessments of Patient Symptoms, Needs, Interventions and Follow-up

During routine consultations, many symptoms are missed or unaddressed. Systematic symptom assessments using a set of standardised tools to ask the patient for his/her needs, symptoms, toxicities and current challenges in everyday life make doctors aware of symptoms and unmet needs otherwise not detected. A selected set of patient-reported outcome measures (PROMs) should be defined as a part of the standard patient assessment in any oncology and/or palliative care unit and utilised at

regular intervals, the timing of which should be defined in standardised care pathways (see above). Rather than the traditional individual physician-dependent assessment and referral, this will increase the likelihood of referral and facilitate timely patient-centred interventions based on needs and not only on prognosis. The scores must be documented on demand in the patient's records. Symptom scores above predefined levels should then always prompt interventions and/or referral to MDTs or palliative care specialists. Adequate, evidence-based interventions according to supportive/palliative care guidelines must follow such assessments, and the effects of the interventions implemented in response to the assessments must again be followed up and assessed systematically.

Research

The financial resources allotted to palliative care research are usually low. The developments in tumour-directed treatment approaches lead to cancer being considered more as a chronic disease and give opportunity to incorporate supportive and palliative care research into oncology research programmes. National healthcare authorities must prioritise integrated research programmes and projects specifically. Research areas could be concentrated on three levels:

1. System-oriented studies on the implementation of models of care, integration and how to implement evidence-based knowledge;
2. Patient-oriented studies to examine symptoms, communication and decision-making; and
3. Public health-oriented studies on the external validity of research findings and implementation strategies.

ESMO Designated Centres of Integrated Oncology and Palliative Care

Since 2003, ESMO has awarded the 'ESMO Designated Centres of Integrated Oncology and Palliative Care' accreditation. The overall aim of this programme is to promote the integration of palliative care services into existing cancer care programmes (<https://esmo.org/designated-centres>).

This fast-growing community consists of cancer centres which provide comprehensive services in supportive and palliative care. Centres self-nominate and are then reviewed via a rigorous anonymous process by members of the ESMO Designated Centres Working Group, to ensure that they fulfil the 13 criteria related to advanced programme development, consistent with the established international standards. These criteria are based on recommendations from the World Health Organization guidelines on the provision of palliative care for patients with cancer regarding integration, credentialing, service provision, research and education. The ESMO Designated Centres have a great potential for collaboration between centres for service development and implementation, education and research. The ESMO Designated Centres Working Group has the ambition to contribute to improvement in all of these areas in the coming years. We will need your contributions today and in the future. For any input or active contributions to the programme, contact: designatedcentres@esmo.org for more information.

Declaration of Interest:

Dr Yri has reported no potential conflicts of interest.

Dr Jordan has reported no potential conflicts of interest.

Dr Kaasa has reported no potential conflicts of interest.

Further Reading

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