



## Supporting Supportive Care in Cancer: The ethical importance of promoting a holistic conception of quality of life



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### ABSTRACT

Advances in anticancer therapies and increasing attention towards patient quality of life make Supportive Care in Cancer (SCC) a key aspect of excellence in oncological care. SCC promotes a holistic conception of quality of life encompassing clinical, ethical/existential, and spiritual dimensions. Despite the calls of international oncology societies empirical evidence shows that SCC has not yet been implemented. More efforts are needed given the clinical and ethical value of SCC not only for patients, but also for clinicians and hospitals.

Drawing on different literature sources, we identify and discuss three important barriers to the implementation of SCC: 1) organisational – lack of adequate resources and infrastructures in over-stretched clinical environments, 2) professional- burnout of cancer clinicians; and 3) cultural – stigma towards death and dying.

We add an ethical counselling framework to the SCC implementation toolkit- which, could offer a flexible and resource-light way of embedding SCC, addressing these barriers.

### 1. Introduction

Medical advances in oncology have led to an increase in cancer survival rates; more patients are cured or live longer with cancer. However, not only cancer treatments, but also receiving a diagnosis (Jutel, 2016), can have major health and psychosocial impact for patients. Therefore addressing the clinical and psychosocial dimensions of cancer in a timely manner can improve the quality of life of patients and increase survival rates (Jordan et al., 2018). This is why supportive care in cancer (SCC) is increasingly seen as a key aspect of the excellence of oncological care.

Despite the clinical and ethical value of SCC, and the high level of consensus about the need to integrate it in standard oncological practice (Jordan et al., 2018; Surbone et al., 2010; Roila et al., 2015), the implementation of SCC still has a long way to go world-wide. Most services still consider SCC a resource to be used after curative care (Murray et al., 2005; Lynn and Adamson, 2003). When available, SCC services are often accessed by chance, and are often not integrated with oncological practice (Ko et al., 2014; Etkind et al., 2017). The implementation of evidences coming from biomedical research is a widely investigated and very challenging phenomenon (Moher et al., 2016) – in oncology, as in other medical specialities. Interestingly, the model of

supportive care we are discussing was first developed almost 15 years ago in geriatric medicine (Lynn and Adamson, 2003), therefore SCC is not even an entirely new care paradigm in medicine.

In this paper we bring together different literature sources to identify and discuss barriers to the implementation of SCC. We searched the literature on SCC, implementation, clinical staff wellbeing, biomedical humanities intended in a wide sense (Annoni et al., 2012) in three databases PubMed, Web of Science, and Google Scholar. In our search strategy we searched for publications with the key terms in the title and/or abstract including: ‘supportive care’, ‘palliative care’, ‘end of life care’, ‘cancer trajectory’, ‘patient and family centered care’, ‘participatory oncology’, ‘intervention’, ‘implementation’. Inclusion criteria for articles were English-language commentaries, reviews, papers. We also searched relevant journals separately, as well as the references of our initial finds, to ensure we had not omitted any relevant literature.

The analysis of the literature allowed us to identify three key barriers to the implementation of SCC: 1) resource and organisational – lack of adequate resources and infrastructures, 2) professional- physician and health care provider burnout, and 3) cultural – stigma towards death and dying.

We further contribute to the body of literature analysed by adding to the SCC implementation toolkit an ethical counselling and medical

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decision-making framework developed by Boniolo and Sanchini (2016). We suggest that while being not too resource-intensive, this framework could help to embed SCC in the current oncological practice, addressing the above-mentioned barriers.

### 1.1. What is Supportive Care in Cancer and what are the problems it raises?

There is not a precise definition of SCC. This is probably because SCC includes – and is sometimes also conflated with – palliative care, end of life care (also referred to as ‘hospice care’), and other terms such as ‘early palliative care’, or ‘early palliative and supportive care’ (Hui et al., 2013; Klastersky et al., 2016). Table 1 provides a terminological clarification of the different meanings/aspects attributed to SCC; this is complemented by Fig. 1 which shows a conceptual framework for SCC, palliative and hospice care (taken from Hui and Bruera (2016)).

Acknowledging the abovementioned semantic difficulties, it is possible to identify some core tents of SCC. SCC deals with clinical and psychosocial needs of cancer patients in order to provide optimal quality of life (Klastersky et al., 2016). SCC includes control of acute complications of cancer and/or its therapy; the management of pain, chronic complications and psychosocial support once oncological therapy is no longer curative; and the approach of the end of life. Therefore, SCC can address all stages of cancer: curative, palliative and terminal treatment (Hui et al., 2012).

The integration of SCC within the illness trajectory can be used by clinicians to conceptualise SCC within patients’ care (although, as mentioned above, this concept is taken from geriatrics). Notably, it shows how elements of supportive care can start very early in the cancer trajectory – and that, ideally, care should not stop with the death of the patient but may involve bereavement care for their family/caregivers.

SCC has a strong ethical value, as it considers patients’ needs holistically. It goes beyond the biomedical dimension of cancer to encompass the ethical/existential and psychosocial dimension of illness, thus honouring the important clinical principle of patient centeredness. Moreover, SCC is also underpinned by a professional and ethical obligation of honesty and transparency towards patients receiving a diagnosis or starting any treatment, to provide them (if they so wish) with comprehensive information about the clinical and care pathways available. SCC includes preparing the patient with non-curable cancer for the reality of available treatment possibilities, avoiding over treatment which may interfere with the preservation of an optimal well-being. Thus, SCC promotes more realistic and professionally meaningful dialogues with patients. While realistic expectations about prognosis are important, the patient-centeredness of SCC implies that the level and amount of such information should be flexible to what patients and family want and need to know, bearing in mind their potentially high vulnerability. Therefore, SCC communication involves many clinical and ethical issues, and requires qualified providers with special expertise. The ethical value of SCC extends beyond the patient. SCC can also empower family members or other caregivers and can help clinicians to plan care in advance. Moreover, a well-implemented SCC may reduce hospital admissions, and may encourage fruitful collaborations between oncology and other medical specialties.

International efforts have been made by medical societies to provide specific guidance on the implementation of SCC or some aspects of SCC within the patient trajectory (Jordan et al., 2018; Surbone et al., 2010; Smith et al., 2012). The importance of SCC is further testified by the fact that it addresses most of the targets identified by the World Cancer Declaration to achieved by 2020 (Cavalli, 2008). These include: availability of cancer-control plans in all countries; dispelling misconceptions about cancer; diagnosis and access to cancer treatment, including palliative care, improved worldwide; universally available effective pain control; greatly improved training opportunities in oncology; major improvement in cancer survival in all countries. Based on the available evidence, the key features and benefits of SCC are summarized in Table 2.

## 2. Implementation challenges

### 2.1. Organisational barriers: lack of adequate resources and infrastructures

SCC often requires multidisciplinary teams (MDT) collaboration, and can be time and resource intensive. However, most health services worldwide are insufficiently funded and experience extraordinary pressure to work with limited resources (World Health Organisation, 2016). It can therefore be very challenging to implement SCC in over-worked healthcare systems, and there is a risk that SCC may be seen by clinicians as an additional unwelcome or unfeasible task. However, from a resource perspective, it is equally important to consider that aggressive cancer treatments can be very expensive (Schrag, 2004). Moreover, lack of appropriate communication between patient and clinicians, and the lack of adequate psychosocial services, may have a negative impact on patient ability to adapt and adjust to cancer, contributing to patient distress, leading to anger, and to an increased risk of litigation based on what could be called *ethical malpractice* (Fallowfield and Jenkins, 2004).

Alongside thinking about resource implications, it is key to ensure that other organisational and infrastructural barriers to the implementation of SCC are removed. Qualitative research reported a mismatch between clinicians’ understanding of patient autonomy and centeredness and the reality of oncology clinical practice. Whilst clinicians see patients’ preferences as central to decision-making, they also highlight how organisational factors such as competing clinical and administrative responsibilities, and structural limitations to care (e.g. barriers to obtaining approval for systemic therapies) may ultimately limit patient choice (Johnson et al., 2018). Compliance points, meeting targets, financial rewards can subvert oncologists’ professionalism, directly or indirectly impeding discussions about the possible dimension of care available to the patients beyond cancer treatment. Clinicians often have to justify why patients *are not* following certain treatment pathways (prescribed by regulatory bodies), or they – or the hospital/service they work in – can receive financial rewards based on the number of certain specific treatments prescribed (McCartney, 2014). These few examples illustrate how the professional autonomy of clinicians is a paramount – but often backgrounded – aspect to the achievement of genuine patient autonomy and centeredness. Charlotte Williamson, the first chair of the UK Royal College of General Practitioners’ patient liaison group, vividly highlights how the realisation of patient centeredness and autonomy requires autonomy also from healthcare professionals: “Patient autonomy requires that the patient be free of coercion, whether overt or covert. The doctor too must be free of coercion, free to explore values, perspectives, anxiety and clinical evidence, free to discuss all possible courses of action with the patient” (Heath, 2012). This important observation is linked to ethical debates about the *relational nature of autonomy* – which recognise that individuals are immersed in a network of relations and interdependencies (Prainsack and Buyx, 2017). As already discussed in the delineation of the key features of SCC (see Table 2), such network includes clinicians, but also other actors such as family members and caregivers. Acknowledging the relationality of patient autonomy is vital to the successful implementation of patient centeredness in SCC (and in other clinical settings).

### 2.2. Professional barriers: burnout of cancer professionals

There are elevated rates of burnout among cancer professionals worldwide: a recent study suggest a prevalence of 35% in medical oncologists, 38% in radiation oncologists, and 28% to 36% in surgical oncologists (Shanafelt and Dyrbye, 2012)<sup>1</sup>. Burnout can impact the quality of care received by patients, but it also has potentially profound

<sup>1</sup> See also <https://am.asco.org/professional-burnout-and-oncology-workforce-perspective-physician-assistants-and-nurse-practitioners>.

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