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

D. Carrieri [1], F.A. Peccatori [2*], G. Boniolo [3]

1 Medical School & Wellcome Centre for Cultures and Environments of Health, University of Exeter, UK; d.carrieri@exeter.ac.uk   ORCID ID: 0000-0002-3143-8430
2 European School of Oncology and European Institute of Oncology, Milan, Italy; fpeccatori@eso.net and fedro.peccatori@ieo.it   ORCID ID: 0000-0001-8227-8740
3 Dipartimento di Scienze Biomediche e Chirurgico Specialistiche, Università di Ferrara, Italia; giovanni.boniolo@unife.it ORCID ID: 0000-0003-1968-4249

Address correspondence to:

Dr F.A. Peccatori, Division of Gynecological Oncology, Fertility and Procreation Unit, European Institute of Oncology, Via Ripamonti 435, Milan 20141, ITALY. +39(2)57489685 fedro.peccatori@ieo.it

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.

Keywords: Cancer; Supportive Care; Ethical Counselling; Palliative Care; Implementation; Illness trajectory

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 [1], 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 [2]. 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 [2-4], 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 [5, 6]. When available, SCC services are often accessed by chance, and are often not integrated with oncological practice [7, 8].

The implementation of evidences coming from biomedical research is a widely investigated and very challenging phenomenon [9] – in oncology, as in other medical specialities. Interestingly, the model of supportive care we are discussing was first developed almost 10 years ago in geriatric medicine [6], 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 [10] 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 centred 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 decision-making framework developed by Boniolo et al [11]. 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' [12, 13]. Table 1 provides a terminological clarification of the different meanings/aspects attributed to SCC; this is complemented by Figure 1 which shows a conceptual framework for SCC, palliative and hospice care (taken from [14]).

Table 1 Terminological clarification

Supportive care in cancer /early palliative and supportive care	Prevention and management of the adverse effects of cancer and its treatment at all stages of the illness. It includes three main aspects: control of complications of cancer and/or its therapy; the management of pain, chronic complications and psychosocial support once oncological therapy is no longer curative (see palliative care); and the approach of the end of life
Palliative care	An approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness, when cure is unlikely or not possible. It offers a support system to help patients live as actively as possible until death. So palliative care is a measure that helps but does not cure patient from disease.
End of life/ hospice care	Palliative care when death is imminent

Figure 1 Conceptual framework for SCC, palliative and hospice care (taken from [14]). Under this framework, hospice care is an arm of palliative care which, in turns is an arm of supportive care.
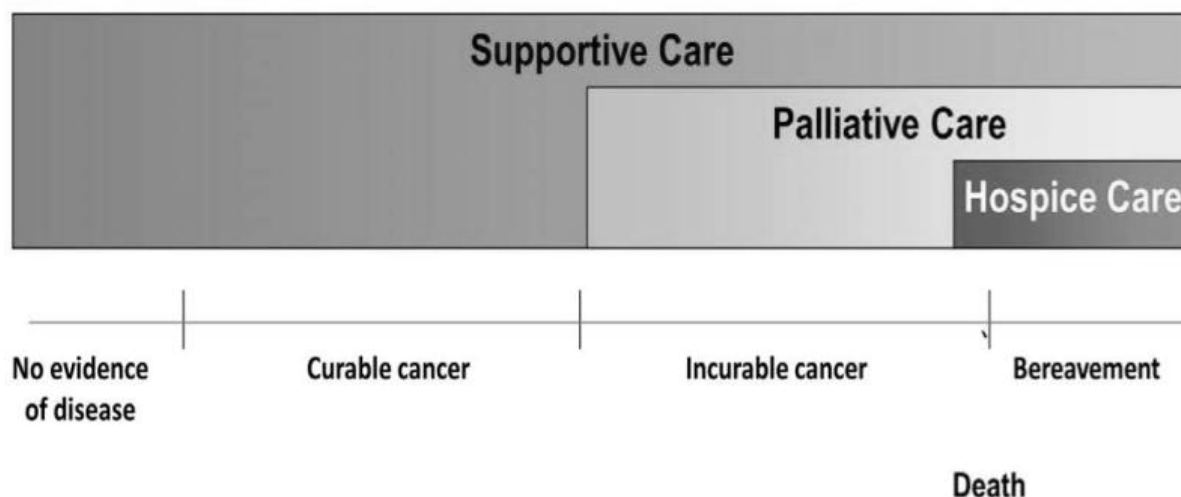
Acknowledging the abovementioned semantic difficulties, it is possible to identify some core tents of SCC. SCC deals with clinical and psychosocial needs of cancer patients in order to provide optimal quality of life [13]. SCC includes control of acute complications of cancer and/or its therapy; the 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 [15].

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 wellbeing. 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 [2, 3, 16]. 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 [17]. 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.

Table 2 Key features and benefits of SCC

Key Feature of SCC	Benefits & Evidence
Timeliness SCC should be integrated with the illness trajectory from cancer diagnosis and throughout the continuum of disease (including end of life and survivorship care).	The time of diagnosis is often also a very stressful time when patients can be vulnerable [18]. Patients tend to become informed and confident in their input into the decisions affecting them as the cancer trajectory unfolds. However the time of diagnosis is already a point in which key decisions are required and most medical and psychosocial issues of survivorship or end of life care begin [19]. It is important to highlight that patients who have early access to palliative approaches (an aspect of SCC) -whether their cancer is advanced or not- have better quality of life; reduction in hospital admissions and in aggressive cancer treatments at the end of life (and more home or hospice deaths)[20]; and live longer than those who receive standard care [18].
Patient centeredness Clinicians should involve patients (and family/care givers) in the decision-making process to address individual preferences, respecting their wishes and vulnerability. SCC should be flexible to the patient, and patient (or guardian) consent should be required.	Patient centeredness is an important tenet not only of SCC and oncology [21], but also of healthcare in general. Patient centered approaches promote patient' feeling of self-efficacy which in turn lead to more favourable outcomes [22], fewer hospitalisation and increased survival rate [23]. Subjective theories of illness should also be considered as they may provide an opportunity to recognise patient need for support [24]. There can be significant conflicts between patient and family (and care givers) regarding treatment decisions [25]. Functional interactions among families, patients, and clinicians are essential to promote good decisions and quality of life. In case of conflicting views about therapy with patients (and their family/caregivers), clinicians should be able to achieve a common *therapeutic goal* [26] with the patients. Both patients and family members can benefit from various forms of psychological intervention. Therapeutic goals need to be reviewed regularly as patients' preferences/needs can change.

Multispecialty SCC requires multidisciplinary teams (MDT) of medical and non-medical professionals that can care for a variety of physical, psychological, social and ethical/existential needs of patients. The tasks and responsibilities of these MDT should vary around the needs of patients. However, the oncologist who normally execute the diagnosis and is in charge of treatment and care should act as a coordinator.	The medical and psychosocial aspects that SCC could cover can be incredibly complex and variable, as is cancer. They can encompass: the management of therapy heterogeneity [27] and polypharmacy (e.g. interaction of antidepressants with anticancer agents[28]), oncofertility [29], end of life care for children and adolescents [30], art interventions to alleviate the chemotherapy related distress [31]. It should also be stressed that complications can continue to occur 20 to 30 years after treatment – this requires prolonged follow-up which are necessarily associated to psychological stress [13]. Disease trajectory parallels – e.g. with non-malignant cardiorespiratory diseases [5] – make MDT and multi-speciality dialogue even more vital. MDT should be responsive to the different cultural background of patients (and family and /caregivers), and sensitive to the different health values and attitudes of each patient [32]. Being open and responsive to patients' culture and spirituality is an important feature of SCC [33]. Patients' spiritual claims may also mask denial or unresolved conflicts, requiring patient referral for proper counselling.
Training and Research More training and research are needed to help clinicians, MDT and patients navigate the difficult clinical ethical legal and psychosocial issues that SCC can present.	SCC requires specific education and training that are not yet provided in most medical schools or at ongoing stages of career development. Clinicians involved with dying patients should consider their own preferences and views of a good death and recognise that these values may not be shared by the patient they are caring for [34]. Clinicians may also need to be trained in leadership/management and communication training to effectively work in MDT[2].

2. Implementation challenges

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 [35]. It can therefore be very challenging to implement SCC in overworked 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 [36]. 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* [37].

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 [38]. 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 [25].
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" [39]. 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 [40]. 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) 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 [41] [1]. Burnout can impact the quality of care received by patients, but it also has potentially profound implications for oncologists (and healthcare systems), including suicidal ideation, desire to retire early, and leaving the profession altogether.
The burnout of oncologists, and of the clinical workforce in general, is a very complex and widespread problem which blends individual, organisational and cultural aspects [42]. The main reported factors associated to burnout in oncology specialists include: feeling of isolation and lack of time to connect with colleagues [43]; feeling unsupported after difficult deaths; difficulties conceptualizing a "good" versus "bad" death [44]; difficulties breaking bad news; difficulties offering end-of-life care and spiritual support; difficulties dealing with cross-cultural issues and in dealing with patients' families [45].
Most of the suggested solutions comprise: communication training aimed at improving oncologists' relationships with patients (and families/caregivers), and with MDT [46]; debriefs; and self-care and awareness plans for oncologists, particularly those who care for patients with life limiting cancer [47]. These solutions echo the aforementioned idea of

---

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

relationality of patient autonomy in SCC (and care in general) – highlighting how it can be equally important for clinicians to be equipped with tools to deal with the clinical and emotional demands of delivering care for cancer patients. Interestingly, most of the causes of and suggested solutions to oncologists' burnout are addressed by SCC. The need for more research and training (to improve patient communication), the emphasis on the ethical value of caring for different aspect of patient quality of life (e.g. existential/spiritual), the value of introducing palliative care early in the illness trajectory, and the importance of MDT work are in fact key features of SCC. Therefore, alongside benefiting patients, adequate implementation of SCC may also help to address the issue of oncologists' burnout.

3) Cultural barriers: stigma towards death and dying

To put it bluntly, adequate (therefore also timely) implementation of SCC ultimately entails discussing openly the possibility of – and when necessary thinking about and planning – death and dying, early in the cancer trajectory. This core aspect of SCC is a much entangled implementation hurdle. Researchers from diverse disciplinary backgrounds have highlighted a tendency in our society to regard death as 'a' or 'the' great enemy and/or as a taboo. This tendency foregrounds the idea of *cure*, and deflects attention towards disease, suffering, and *care* – three pillars of SCC.
In the past, dying at home with relatives was the norm, death was more integrated with life and it was made more tolerable by the social and religious environment [48]. Currently more than half of the deaths in industrialised counties occur in hospitals (often in Intensive Care Units). Death and dying have been made 'invisible' and 'controlled' through hospitalisation [49]. They tend to be treated as a medical problems or failure, rather than natural events [50]. This makes dying less socially personalised and may prolong and disrupt the bereavement process [13]. The consequent trauma can in turn feed the fear and stigma towards death.

The difficulty in planning SCC and discussing prognostic uncertainty is often underpinned by such stigma [50]. Clinicians tend to view disclosing uncertainty as potentially damaging to the doctor-patient relationship and often give falsely optimistic prognosis to dying patients [25]. These 'optimistic' prognoses can lead patients to pursue intense – even experimental and potentially harmful [51] – treatments near the end of life, at the expense

of palliation. Oncologists have expressed concern that a referral to palliative care would destroy patient's hope [52]. Cancer centres homepages rarely mention palliative care services, while webpages with palliative care content sometimes omit information about early use of care [53].

Studies showed that patients attach a strong stigma to palliative care, even after a positive experience with early palliative intervention [54]. However, there seem to be no evidence that prognostic disclosure makes patients less hopeful. There is instead evidence that disclosure of prognosis can support hope, even when the prognosis is poor [55].

Moreover widespread metaphors of 'war' and 'fight' [56] are not only misleading but also dangerous, as the pressure to be 'positive' can hinder patients/families caregivers to talk about fears [57] and may ultimately obstruct decision making – biasing it towards aggressive treatments[25]. The media can also contribute to nurturing this cultural trope of 'fight' by offering often an over-optimistic view of the success of medical treatments [58].

More research on the impact of prognosis communication on patient outcomes is needed to improve prognostic discussion [59].

Notably, studies have shown how the term 'supportive care' seems to be much better received by patients than other terms such as 'palliative care' [60]. Moreover there is evidence that addressing anxiety/fear towards death can reduce clinicians burnout and improve patient outcomes [61]. The idea of improved and more comprehensive communication about the risks and benefits of aggressive cancer therapy and of other options offered by SCC would more often discourage potentially harmful intensive treatment and encourage autonomous and meaningful choices. Referrals to palliative care and hospice services often occur much too late to provide substantial benefit, if the referrals occur at all [62].

3. Supporting SCC

More efforts need to be made to implement SCC, given the enormous benefits of SCC not only for patients, but potentially also for clinicians and hospitals. SCC can improve symptoms, reduce hospital costs, optimise the planning and coordination of care [63]. It can reduce inappropriate hospital admission[64], costs in healthcare systems [65], burnout and retention of staff.

It is very challenging to suggest a detailed and unique model of the implementation of SCC given the cultural differences in patients' and families' health beliefs and values, as well as organisational, resource, ethical and policies difference across countries. There has been a call for the importance of involving patients, clinicians and other stakeholders - to co-design and embed the key features of SCC at local hospital level [66]

However, while being flexible, the implementation of SCC should also be equitable [24], as ethnic and socioeconomic differences in advance care planning and death rate have been reported [67] .

3.1 Ethical counselling

In order to 'support' SCC, we would like to add to the SCC implementation toolkit a particular type of ethical counselling (EC) framework developed by Boniolo et al [11]. This EC framework has been developed to improve patients' awareness on the ethical choices they may be asked to make whenever clinical options raise ethical dilemmatic situations. It is based on two ethical decision-making methodologies, one addressing the patients, the other the doctor, and it promotes decisions that are informed and in line with patients' personal philosophies. The term personal philosophy refers to the "wide set of more or less deep, coherent and justified metaphysical, methodological, religious, political, esthetical, ethical, etc., beliefs, assumptions, principles, and values that an agent possesses and that characterises in a unique way how he/she approaches the world and life. […] The 'conceptual and value-laden window' from which any individual starts reflecting in order to make judgments, to make choices, and to act", [11:p. xiii].

This framework is in line with the relational view of autonomy (see sections 2.1, 2.2 and [40]), and with research conducted on truth disclosure in oncology [68]. However it has not yet been not considered in the SCC literature.

EC can be an additional tool to help to embed SCC in the cancer trajectory as it is flexible, directed at patients and health care providers and it is sustainable. It can also address most of the problems related to SCC and the three implementation barriers we have highlighted. In particular:

- It can help to reduce *language and definition confusion* around SCC – an important role of the EC is clarification of language and to make patients' and clinicians' potentially misleading assumptions explicit

- Being a bidirectional reflective tool aimed at both patients and clinicians, EC can help clinicians to *improve their communication skills*, while potentially sharing some of the communication task, *reducing clinicians' burnout, and introducing elements of training*.

- EC can help *both* clinicians and patients to *address anxiety and fear of death* which can otherwise hinder adequate understanding of options available and decision making- thus reducing clinicians' burnout and improving patients' outcomes.

- EC takes into account *cultural and spiritual variations and needs,* also in relation to *how much and how to convey information*

- It is *patient centered* and aims to improve decision-making by placing emphasis on the communication of the relevant information, in a way that is *responsive to patients' personal philosophies and needs*.

- It can help *patients, professionals and families/ care givers to* address conflicts and *achieve a common therapeutic goal.*

Although oncologists should have a critical coordinative role in providing supportive care, it is unrealistic to expect them to address the many dimension of patients' needs [14] covered by SCC. Moreover, patients have reported that they prefer their oncologists to be optimistic about treatment options and to avoid pessimistic discussion about end of life care; suggesting that oncologists who focus on cancer treatment and physiological symptom relief rather than psychosocial of existential issues may be more desirable [69]. Patients often prefer to discuss advance care planning with a clinician who they have never met rather than their own clinical oncologist [70]. This is one of the reasons why MDT are crucial. While implementing MDT can be a long and resource-intensive process, introducing ethical counsellors could help fostering MDT work. They could relieve the ethical/spiritual burden on oncologists, and act as gatekeeper between oncologists and other specialities.

Given the inherent asymmetry of the patient-doctor relationship, it is especially important for oncologists to be aware of the difficulties and potential risks of acting as ethical/existential or spiritual advisors. This role requires specific education and training that

are not yet provided in most medical schools. Yet in most clinical practices worldwide, physicians and nurses are often called to address the spiritual concerns of their patients (potentially contributing to professional burnout). Spiritual teams are becoming common addition to SCC's MDTs. They generally consist of hospital chaplains or spiritual advisors trained to address patient spirituality along with cancer survivors, volunteers, and interested oncology professionals [3]. The ethical counsellor may not only contribute to the emergence of such 'spiritual teams', but – as they work with both patient and clinicians - ethical counsellors can at the same time improve the care received by patient and provide support and communication training to the clinician. This makes ethical counselling a very valuable (low investment/big gain) resource to organise SCC.

4. Conclusions

Alongside biomedical treatments and cure, the ethical /existential dimensions of care are very important in cancer – as with many other conditions which can cause suffering. In cancer care, the integration of SCC in standard oncology practice is of enormous benefit to patients, their families and caregivers, clinicians, and hospitals. Nevertheless, despite these benefits - testified also by the efforts of international societies to integrate SCC – SCC is still mostly considered as a resource to be used after curative care.

We have identified three challenges (lack of resources and organisational infrastructures, professional burnout, and stigma towards death and dying) which we think should be considered in future SCC implementation strategies. To support SCC, we have also added an ethical counselling framework to the SCC implementation toolkit, arguing that the framework could offer a sustainable way to embed SCC, addressing the three challenges.

As discussed, the implementation of SCC needs to be flexible towards differences in organisation, resources, and policies across countries. At the same time it needs to be equitable – therefore underpinned by a set of universal principles. As they would work with both patients and clinicians (and other stakeholders in hospitals), ethical counsellors could help to embed these principles in local contexts, becoming advocate for change.

Conflict of Interests

The authors declare no conflict of interest

Vitae

Daniele Carrieri is a Research Fellow at the Medical School and at the Wellcome Centre for Cultures and Environments of Health, both based at the University of Exeter.

Fedro Alessandro Peccatori is Scientific Director at the European School of Oncology and Director of the Fertility and Procreation Unit at the European Institute of Oncology, Milan, Italy.

Giovanni Boniolo has the chair of Philosophy of Science and Medical Humanities at the Medical School of the University of Ferrara: http://docente.unife.it/giovanni.boniolo

References

1. Jutel, A., *Truth and lies: Disclosure and the power of diagnosis.* Social Science & Medicine, 2016. **165**: p. 92-98.
2. Jordan, K., Aapro, M., Kaasa, S., et al., *European Society for Medical Oncology (ESMO) position paper on supportive and palliative care.* Annals of Oncology, 2018. **29**(1): p. 36-43.
3. Surbone, A., Baider, L., Weitzman, T.S., Brames, M.J., Rittenberg, C.N., Johnson, J., *Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement.* Support Care Cancer, 2010. **18**(2): p. 255-63.
4. Roila, F., Ripamonti, C.I., Antonuzzo, A., Bossi, P., *NICSO: Network Italiano Cure di Supporto in Oncologia--Italian Network for Supportive Care in Oncology.* Support Care Cancer, 2015. **23**(1): p. 11-2.
5. Murray, S.A., Kendall, M., Boyd, K., Sheikh, A., *Illness trajectories and palliative care.* Bmj, 2005. **330**(7498): p. 1007-11.
6. Lynn, J., Adamson, D.M., *Living well at the end of life. Adapting health care to serious chronic illness in old age*. 2003, RAND CORP SANTA MONICA CA.
7. Ko, W., Deliens, L., Miccinesi, G., et al., *Care provided and care setting transitions in the last three months of life of cancer patients: a nationwide monitoring study in four European countries.* BMC Cancer, 2014. **14**: p. 960.
8. Etkind, S.N., Bone, A.E., Gomes, B., et al., *How many people will need palliative care in 2040? Past trends, future projections and implications for services.* BMC Med, 2017. **15**(1): p. 102.
9. Moher, D., Glasziou, P., Chalmers, I., et al., *Increasing value and reducing waste in biomedical research: who's listening?* Lancet, 2016. **387**(10027): p. 1573-86.
10. Annoni, M., Schiavone, G., Chiapperino, L., Boniolo, G., *Constructing the Medical Humanities gaze.* Critical reviews in oncology/hematology, 2012. **84**: p. S5-S10.

11.   Boniolo, G., Sanchini, V., *Ethical Counselling and Medical Decision-Making in the Era of Personalised Medicine*. Counselling and Medical Decision-Making in the Era of Personalised Medicine: A Practice-Oriented Guide, ed. G. Boniolo, V. Sanchini. 2016: Springer International Publishing.

12.   Hui, D., De La Cruz, M., Mori, M., et al., *Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.* Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer, 2013. **21**(3): p. 659-685.

13.   Klastersky, J., Libert, I., Michel, B., Obiols, M., Lossignol, D., *Supportive/palliative care in cancer patients: quo vadis?* Support Care Cancer, 2016. **24**(4): p. 1883-8.

14.   Hui, D., Bruera, E., *Integrating palliative care into the trajectory of cancer care.* Nature reviews. Clinical oncology, 2016. **13**(3): p. 159-171.

15.   Hui, D., Mori, M., Parsons, H.A., et al., *The Lack of Standard Definitions in the Supportive and Palliative Oncology Literature.* Journal of Pain and Symptom Management, 2012. **43**(3): p. 582-592.

16.   Smith, T.J., Temin, S., Alesi, E.R., et al., *American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care.* J Clin Oncol, 2012. **30**(8): p. 880-7.

17.   Cavalli, F., *The World Cancer Declaration: a roadmap for change.* Lancet Oncol, 2008. **9**(9): p. 810-1.

18.   Thorne, S., Oliffe, J.L., Stajduhar, K.I., *Communicating shared decision-making: cancer patient perspectives.* Patient Educ Couns, 2013. **90**(3): p. 291-6.

19.   Ganz, P.A., *Cancer survivorship: today and tomorrow*. 2007: Springer Science & Business Media.

20.   Henson, L., Gao, W., Higginson, I., et al., *Emergency department attendance by patients with cancer in the last month of life: a systematic review and meta-analysis.* The Lancet, 2015. **385**: p. S41.

21.   Baile, W.F., Aaron, J., *Patient-physician communication in oncology: Past, present, and future.* Current Opinion in Oncology, 2005. **17**(4): p. 331-335.

22.   Chirico, A., Lucidi, F., Merluzzi, T., et al., *A meta-analytic review of the relationship of cancer coping self-efficacy with distress and quality of life.* Oncotarget, 2017. **8**(22): p. 36800-36811.

23.   Basch, E., Deal, A.M., Dueck, A.C., et al., *Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment.* Jama, 2017. **318**(2): p. 197-198.

24.   Preisler, M., Heuse, S., Riemer, M., Kendel, F., Letsch, A., *Early integration of palliative cancer care: patients' and caregivers' challenges, treatment preferences, and knowledge of illness and treatment throughout the cancer trajectory.* Support Care Cancer, 2018. **26**(3): p. 921-931.

25.   McCartney, M., *Living with Dying: finding care and compassion at the end of life*. 2014: Pinter & Martin.

26.   Committee on Bioethics, *Guide on the decision-making process regarding medical treatment in end-of-life situations.* Council of Europe, 2014. **https://rm.coe.int/168039e8c5**.

27.   Garattini, S., Fuso Nerini, I., D'Incalci, M., *Not only tumor but also therapy heterogeneity.* Annals of Oncology, 2018. **29**(1): p. 13-19.

28.   Grassi, L., Nanni, M.G., Rodin, G., Li, M., Caruso, R., *The use of antidepressants in oncology: a review and practical tips for oncologists.* Annals of Oncology, 2018. **29**(1): p. 101-111.

29.   Paluch-Shimon, S., Peccatori, F.A., *BRCA 1 and 2 mutation status: the elephant in the room during oncofertility counseling for young breast cancer patients.* Annals of Oncology, 2018. **29**(1): p. 26-28.

30.   Wiener, L., Zadeh, S., Battles, H., et al., *Allowing adolescents and young adults to plan their end-of-life care.* Pediatrics, 2012. **130**(5): p. 897-905.

31.   Chen, S.C., Chou, C.C., Chang, H.J., Lin, M.F., *Comparison of group vs self-directed music interventions to reduce chemotherapy-related distress and cognitive appraisal: an exploratory study.* Support Care Cancer, 2018. **26**(2): p. 461-469.

32.   Ciemins, E.L., Brant, J., Kersten, D., Mullette, E., Dickerson, D., *Why the Interdisciplinary Team Approach Works: Insights from Complexity Science.* J Palliat Med, 2016. **19**(7): p. 767-70.

33.   Kristeller, J.L., Zumbrun, C.S., Schilling, R.F., *'I would if I could': how oncologists and oncology nurses address spiritual distress in cancer patients.* Psychooncology, 1999. **8**(5): p. 451-8.

34.   Kastbom, L., Milberg, A., Karlsson, M., *A good death from the perspective of palliative cancer patients.* Support Care Cancer, 2017. **25**(3): p. 933-939.

35.   World Health Organisation (WHO) *National Health Workforce Accounts: A Handbook*. 2016: http://www.who.int/hrh/documents/brief_nhwfa_handbook/en/.

36.   Schrag, D., *The price tag on progress--chemotherapy for colorectal cancer.* N Engl J Med, 2004. **351**(4): p. 317-9.

37.   Fallowfield, L., Jenkins, V., *Communicating sad, bad, and difficult news in medicine.* Lancet, 2004. **363**(9405): p. 312-319.

38.   Johnson, S.B., Butow, P.N., Kerridge, I., Tattersall, M.H.N., *Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians' perspectives.* Support Care Cancer, 2018. **26**(2): p. 565-574.

39.   Heath, I., *Love's labours lost. Why society is straitjacketing its professionals and how we might release them. Michael Shea Memorial Lecture. Edinburgh, 10 September 2012;[cited 2013 July 15]*. 2012.

40.   Prainsack, B., Buyx, A., *Solidarity in Biomedicine and Beyond*. Vol. 33. 2017: Cambridge University Press.

41.   Shanafelt, T., Dyrbye, L., *Oncologist burnout: causes, consequences, and responses.* J Clin Oncol, 2012. **30**(11): p. 1235-41.

42.   Carrieri, D., Briscoe, S., Jackson, M., et al., *'Care Under Pressure': a realist review of interventions to tackle doctors' mental ill-health and its impacts on the clinical workforce and patient care.* BMJ Open, 2018. **8**(2).

43.   Balch, C.M., Copeland, E., *Stress and Burnout Among Surgical Oncologists: A Call for Personal Wellness and a Supportive Workplace Environment.* Annals of Surgical Oncology, 2007. **14**(11): p. 3029-3032.

44.   Leff, V., Klement, A., Galanos, A., *A Successful Debrief Program for House Staff.* Journal Of Social Work In End-Of-Life & Palliative Care, 2017. **13**(2-3): p. 87-90.

45.   Deng, Y.T., Liu, J., Zhang, J., et al., *A multicenter study on the validation of the Burnout Battery: a new visual analog scale to screen job burnout in oncology professionals.* Psychooncology, 2017. **26**(8): p. 1120-1125.

46.   Sanchez-Reilly, S., Morrison, L.J., Carey, E., et al., *Caring for oneself to care for others: physicians and their self-care.* The journal of supportive oncology, 2013. **11**(2): p. 75-81.

47.   Curtis, J.R., Vincent, J.-L., *Ethics and end-of-life care for adults in the intensive care unit.* Lancet (London, England), 2010. **376**(9749): p. 1347-53.

48.   Schillace, B., *Death's Summer Coat: What the History of Death and Dying Teaches Us About Life and Living*. 2016: Pegasus Books.

49.   Rothman, D.J., *Where we die.* N Engl J Med, 2014. **370**(26): p. 2457-60.

50.   Gordon, G.H., *Care not cure: dialogues at the transition.* Patient education and counseling, 2003. **50**(1): p. 95-8.

51.   Carrieri, D., Peccatori, F.A., Boniolo, G., *The ethical plausibility of the 'Right To Try' laws.* Critical Reviews in Oncology/Hematology, 2018. **122**: p. 64-71.

52.   Nguyen, T.K., Bauman, G.S., Watling, C.J., Hahn, K., *Patient- and family-centered care: a qualitative exploration of oncologist perspectives.* Support Care Cancer, 2017. **25**(1): p. 213-219.

53. Cherny, N.I., *Stigma associated with "palliative care": getting around it or getting over it.* Cancer, 2009. **115**(9): p. 1808-12.

54. Zimmermann, C., Swami, N., Krzyzanowska, M., et al., *Perceptions of palliative care among patients with advanced cancer and their caregivers.* Cmaj, 2016. **188**(10): p. E217-27.

55. Mack, J.W., Wolfe, J., Cook, E.F., Grier, H.E., Cleary, P.D., Weeks, J.C., *Hope and prognostic disclosure.* J Clin Oncol, 2007. **25**(35): p. 5636-42.

56. Sontag, S., *Illness as Metaphor*. 1979: New York.

57. Frank, A.W., *The Wounded Storyteller: Body, illness, and Ethics*. 2013: University of Chicago Press.

58. Diem, S.J., Lantos, J.D., Tulsky, J.A., *Cardiopulmonary resuscitation on television. Miracles and misinformation.* N Engl J Med, 1996. **334**(24): p. 1578-82.

59. Wittink, M.N., Morales, K.H., Meoni, L.A., et al., *Stability of preferences for end-of-life treatment after 3 years of follow-up: the Johns Hopkins Precursors Study.* Arch Intern Med, 2008. **168**(19): p. 2125-30.

60. Maciasz, R.M., Arnold, R.M., Chu, E., et al., *Does it matter what you call it? A randomized trial of language used to describe palliative care services.* Support Care Cancer, 2013. **21**(12): p. 3411-9.

61. Melo, C.G., Oliver, D., *Can addressing death anxiety reduce health care workers' burnout and improve patient care?* Journal of palliative care, 2011. **27**(4): p. 287.

62. Hoerger, M., *Right-to-try laws and individual patient "compassionate use" of experimental oncology medications: A call for improved provider-patient communication.* Death Stud, 2016. **40**(2): p. 113-20.

63. Mercadante, S., Adile, C., Caruselli, A., et al., *The Palliative-Supportive Care Unit in a Comprehensive Cancer Center as Crossroad for Patients' Oncological Pathway.* PLoS One, 2016. **11**(6): p. e0157300.

64. Cassel, J.B., Kerr, K.M., Kalman, N.S., Smith, T.J., *The Business Case for Palliative Care: Translating Research Into Program Development in the U.S.* J Pain Symptom Manage, 2015. **50**(6): p. 741-9.

65. Ziegler, L.E., Craigs, C.L., West, R.M., et al., *Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study.* BMJ Open, 2018. **8**(1).

66. Cresswell, M.A., Robinson, C.A., Fyles, G., Bottorff, J.L., Sudore, R., *Evaluation of an advance care planning web-based resource: applicability for cancer treatment patients.* Support Care Cancer, 2018. **26**(3): p. 853-860.

67. Jemal, A., Siegel, R.L., Ma, J., et al., *Inequalities in premature death from colorectal cancer by state.* J Clin Oncol, 2015. **33**(8): p. 829-35.

68. Surbone, A., *Telling the truth to patients with cancer: what is the truth?* Lancet Oncol, 2006. **7**(11): p. 944-50.

69. Tanco, K., Rhondali, W., Perez-Cruz, P., et al., *Patient Perception of Physician Compassion After a More Optimistic vs a Less Optimistic Message: A Randomized Clinical Trial.* JAMA Oncol, 2015. **1**(2): p. 176-83.

70. Dow, L.A., Matsuyama, R.K., Ramakrishnan, V., et al., *Paradoxes in advance care planning: the complex relationship of oncology patients, their physicians, and advance medical directives.* J Clin Oncol, 2010. **28**(2): p. 299-304.