Definition of supportive care: does the semantic matter?

David Hui

Purpose of review
‘Supportive care’ is a commonly used term in oncology; however, no consensus definition exists. This represents a barrier to communication in both the clinical and research settings. In this review, we propose a unifying conceptual framework for supportive care and discuss the proper use of this term in the clinical and research settings.

Recent findings
A recent systematic review revealed several themes for supportive care: a focus on symptom management and improvement of quality of life, and care for patients on treatments and those with advanced stage disease. These findings are consistent with a broad definition for supportive care: ‘the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement.’ Supportive care can be classified as primary, secondary, and tertiary based on the level of specialization. For example, palliative care teams provide secondary supportive care for patients with advanced cancer.

Summary
Until a consensus definition is available for supportive care, this term should be clearly defined or cited whenever it is used.

Keywords
definitions, neoplasms, palliative care, supportive care, symptom management

INTRODUCTION: DOES THE SEMANTIC MATTER?

What is in a name? A rose by any name would smell as sweet; however, we have retained its name because we all know exactly what a rose is and are able to recall its dear perfection whenever this term is used. Clear definitions are thus essential for us to communicate effectively. In fact, semantics is particularly important when it comes to patient care and scientific research, in which we need to minimize misconception, misunderstanding, miscommunication, misuse, and mislabels.

‘Supportive care’ is a commonly used term in oncology and carries different meanings for different groups. The National Institute of Health State of Science Conference Statement on Improving End-of-Life Care stated that ‘there has been a lack of definitional clarity related to several concepts and terms. Too often these terms are used interchangeably and the distinctions for each term must be clarified to patients and their families, providers, policymakers, and investigators’ [1]. A recent survey of palliative care specialists revealed that ‘supportive care’ is one of the key terms requiring higher definitional clarity [2]. The lack of a clear definition for this term represents a barrier to communication in both clinical practice and research.

The objective of this review is to discuss the supportive care needs of cancer patients, to examine existing definitions for supportive care, to propose a conceptual framework for supportive care, and to describe the proper use of this term in the clinical and research settings.
Supportive care

KEY POINTS

- Although wide variations exist among the definitions for supportive care, all of them include elements of symptom management and improvement of quality of life for cancer patients on treatments and those with advanced diseases.
- Primary supportive care is delivered by oncologists and primary care teams, providing basic symptom management and information in the front-line setting.
- Secondary supportive care is provided by teams with specialized expertise, such as palliative care, wound care, and psychiatry, on a consultation basis.
- Randomized controlled trials involving a ‘supportive care’ arm should clearly define the level of intervention and ideally involve secondary supportive care services to ensure a high standard of care delivery.

SUPPORTIVE CARE NEEDS OF CANCER PATIENTS

The diagnosis of cancer is associated with significant mortality and morbidity [3]. From the time of diagnosis, cancer patients suffer from a multitude of physical symptoms such as fatigue, pain, nausea, vomiting, constipation, anorexia, and weight loss secondary to a combination of tumor burden, cancer treatments, preexisting comorbidities, and various acute complications [4]. Cancer patients also experience tremendous uncertainties and psychological distress as a result of changes to their survival, function, sexuality, relationships, income, independence, and identities, which are often associated with significant caregiver distress [5]. Moreover, patients and families often have complex communication and decision-making needs for a wide range of topics ranging from prognosis to treatment decisions and end-of-life care planning [6].

Comprehensive cancer care includes not only diagnosis, staging, and treatment of cancer, but also impeccable assessment and management of the above physical, psychological, spiritual, social, and informational needs – collectively known as the supportive care issues (Fig. 1). Because of the diverse care needs, multiple disciplines are involved in addressing them. For instance, oncologists have naturally acquired expertise in the management of cancer treatment related side-effects. Pain specialists are apt at using various pharmacological and non-pharmacological interventions to alleviate pain. Psychiatrists, physiotherapists, and occupational therapists are experts in assisting patients with their rehabilitation and functional needs. Pulmonologists focus on the treatment of pleural effusion, airway obstruction, dyspnea, and cough. Psychologists and psychiatrists often address adjustment disorders, anxiety, and depression. Chaplains are skilled at provision of spiritual care. Social workers are resourceful in coordinating support services in the community.

Recognizing that the supportive care needs often present together and are multifactorial in nature, a number of interprofessional programs have been developed to address these issues in a multidimensional fashion, often focusing on specific populations. For example, palliative care teams, staffed by physicians, nurses, counselors, social workers, chaplains, and others, are experts in addressing the supportive care needs for patients with advanced cancer. Multiple studies have demonstrated that palliative care involvement is associated with improved symptom control, mood, quality of life, quality of care, satisfaction, and even survival [7–9]. These interprofessional supportive care programs have significant advantages over referral to individual branches of supportive care because they allow patients’ needs to be addressed comprehensively, efficiently, and effectively, while minimizing fragmentation in care delivery [10].

DEFINITIONS OF SUPPORTIVE CARE

‘Supportive Care’ first emerged in the 1980s. This term has since been used frequently in the literature and has been variably defined because many disciplines are involved in its delivery. We recently examined a sample of the palliative oncology publications – ‘supportive care’ appeared in 106 of 1213 articles; however, it was only defined in two papers [2*]. A subsequent literature review focusing on articles that aimed at defining ‘supportive care’ or ‘best supportive care’ identified 13 definitions from nine publications, which ranged widely from comprehensive services to a sole focus on treatment-related side-effects [11*]. For instance, Cherny [12] described supportive care as ‘a treatment approach to reduce side-effects from chemotherapy and other primary treatments in cancer to an all encompassing purview that incorporates all aspects of toxicity minimization, palliative care, and survival’.

In contrast, Ritchie and Roboz [13] defined best supportive care for elderly patients with acute myeloid leukemia as ‘treatment with antibiotics, transfusions of blood and blood products, hydroxyurea, and hematopoietic growth factors’.

Based on our literature search, a number of key themes on the definition of supportive care emerged (Table 1):

1. All definitions invariably described some form of symptom control and interventions to
improve quality of life. Other services such as caregiver care and bereavement care were sometimes discussed.

(2) All definitions involved patients with advanced cancer and those receiving treatments or enrolled onto clinical trials or both. Patients with curable cancer and cancer survivors were sometimes mentioned in the definitions.

(3) A majority of investigators expressed concerns that ‘supportive care’ is confusing.

These findings allow us to formulate a conceptual framework based on our current understanding of what supportive care entails (Fig. 2). The definition most consistent with this framework is one that is broadest in scope. Citing the Toronto-Bayview Regional Cancer Centre manual, Page [14] stated that supportive care is ‘the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement’. This definition clearly describes the population (patients and caregivers), time frame (diagnosis, survivorship, prevention, and bereavement), and domains of care (physical, emotional, spiritual, social, and informational).

Building on this comprehensive definition, Cherny [15] further proposed a number of standards for supportive care programs:

1. Adequate staff training for primary level providers of supportive and palliative care including oncologist and oncology nurses to ensure appropriate knowledge skills and attitudes in supportive and palliative care.
2. Interdisciplinary care with a minimum team of physician, nurse, and social worker.
3. Care coordinated to minimize the burden on patient, their caregiver(s), and family.
4. Routine patient evaluation using validated tools to evaluate the prevalence and severity of supportive care issues.
of physical and psychological symptoms and the adequacy of social supports.

(5) Treatment of physical symptoms, including pain, with evidence-based approaches and validated care pathways.

(6) Patient monitoring for the adequacy of relief, and adjustment of treatment strategies as necessary.

(7) Access to specialist palliative or pain management care for patients and situations that exceed the capabilities of the primary level care providers.

(8) Meticulous management of the adverse effects of treatment.

(9) Availability of psychological and spiritual care for patients and their family members.

(10) Ongoing care planning based on ongoing assessment, determined by goals set with patient and family, and with consideration of the changing benefit/burden of any treatment strategy.

**A CONCEPTUAL FRAMEWORK FOR ‘SUPPORTIVE CARE,’ ‘PALLIATIVE CARE,’ AND ‘HOSPICE CARE’**

‘Supportive care,’ ‘palliative care,’ and ‘hospice care’ are sometimes used interchangeably, which is confusing to clinicians and patients alike [16–18]. To understand these concepts better, we conducted a systematic review to identify defining features for these three terms (Table 1) and developed a preliminary conceptual framework unifying these terms along the continuum of care (Fig. 2). Under this framework, ‘Hospice care’ focuses on providing care for patients at the end-of-life (i.e. last 6 months) predominately in the community setting. ‘Palliative care’ includes not only hospice care services, but also acute palliative care programs in hospitals providing care for patients with advanced diseases. ‘Supportive care’ is the most encompassing term that spans survivorship care services to bereavement programs for patients throughout the disease trajectory [11**].

**USE OF ‘SUPPORTIVE CARE’ IN THE CLINICAL SETTING**

Based on our conceptual model (Fig. 2), supportive care services may or may not be palliative in nature, but all palliative care programs are by definition providing supportive care for patients with advanced cancer. In a recent survey of oncologists and mid-level providers at our institution, a majority of them perceived that the term ‘supportive care’ was less likely to cause distress in patients and families compared to ‘palliative care.’ They also reported that they felt more comfortable to refer patients to a ‘supportive care’ service instead of a ‘palliative care’ service [19]. Based on these findings, we changed our program’s name from ‘palliative care’ to ‘supportive care.’

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**Table 1. Conceptual elements among ‘best/supportive care,’ ‘palliative care,’ and ‘hospice care’ [11**]**

<table>
<thead>
<tr>
<th>Conceptual elements</th>
<th>Best supportive care or supportive care, N = 9 (%)</th>
<th>Palliative care, N = 25 (%)</th>
<th>Hospice care, N = 12 (%)</th>
<th>P value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom control/quality of life</td>
<td>9 (100)</td>
<td>24 (96)</td>
<td>12 (100)</td>
<td>&gt;0.99</td>
</tr>
<tr>
<td>Caregiver care</td>
<td>5 (56)</td>
<td>22 (88)</td>
<td>11 (92)</td>
<td>0.06</td>
</tr>
<tr>
<td>Bereavement care</td>
<td>1 (11)</td>
<td>6 (24)</td>
<td>9 (75)</td>
<td>0.003</td>
</tr>
<tr>
<td>Patient population</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients on treatment/trials</td>
<td>9 (100)</td>
<td>8 (32)</td>
<td>0 (0)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Patients with advanced, noncurable disease</td>
<td>9 (100)</td>
<td>25 (100)</td>
<td>12 (100)</td>
<td>–</td>
</tr>
<tr>
<td>Patients with curable disease</td>
<td>4 (44)</td>
<td>12 (48)</td>
<td>0 (0)</td>
<td>0.006</td>
</tr>
<tr>
<td>Service providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interprofessional care</td>
<td>4 (44)</td>
<td>20 (80)</td>
<td>11 (92)</td>
<td>0.05</td>
</tr>
<tr>
<td>Volunteer involvement</td>
<td>0 (0)</td>
<td>6 (24)</td>
<td>6 (50)</td>
<td>0.03</td>
</tr>
<tr>
<td>Settings</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Community-based program</td>
<td>0 (0)</td>
<td>6 (24)</td>
<td>9 (75)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Inpatient program</td>
<td>0 (0)</td>
<td>10 (40)</td>
<td>6 (50)</td>
<td>0.03</td>
</tr>
<tr>
<td>Perception</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Term described as confusing</td>
<td>7 (78)</td>
<td>11 (44)</td>
<td>5 (42)</td>
<td>0.23</td>
</tr>
<tr>
<td>Term described as euphemistic</td>
<td>2 (22)</td>
<td>8 (32)</td>
<td>2 (17)</td>
<td>0.67</td>
</tr>
<tr>
<td>Term associated with fear</td>
<td>1 (11)</td>
<td>4 (16)</td>
<td>5 (42)</td>
<td>0.20</td>
</tr>
</tbody>
</table>

*Fisher’s exact test.
care’ to ‘supportive care’ in 2007. Compared to prename change period, we documented an increased number of inpatient palliative care referrals and also earlier referrals in the outpatient clinic in the postname change period [20].

Although some may argue that the use of supportive care to describe a palliative care program is euphemistic, we believe the use of this name is appropriate, particularly when a palliative care program expands its services to patients with curable disease. For instance, our program routinely provides consultation and followup for patients with curable head and neck cancer undergoing chemoradiation [21,22]. Indeed, hybrid terms such as ‘supportive and palliative care’ and ‘supportive and palliative oncology’ have gained popularity as program names, journal titles, and publication headings [23–26].

Similar to the classification for palliative care services [27], supportive care may be divided into three levels based on the level of specialization:

1. Primary supportive care is delivered by primary care teams and oncologists in the front line. For instance, oncologists often provide recommendations for prophylaxis and management for treatment-related adverse effects, and some consistently initiate prognostic discussions and advance care planning with their patients. Because of limitations in clinic time, training, ability to keep up with the supportive care literature, and clinic resources, they may not be able to fully address the supportive care issues in complex patients and would need to refer patients to secondary supportive care teams.

2. Secondary supportive care involves specialized teams that address one or more supportive care domains, such as psychiatry, pulmonary medicine, wound and ostomy care, and palliative care teams. These services may be accessed via inpatient consultation or outpatient clinics or both.

3. Tertiary supportive care involves these specialized teams providing care to patients with the most complex supportive care needs in tertiary care settings, such as acute palliative care units. These teams are also

FIGURE 2. A conceptual model for supportive care, palliative care, and hospice care. Supportive care includes the widest scope of services, ranging from survivorship programs for cancer survivors to bereavement care for bereaved caregivers. Palliative care provides supportive care to patients with advanced cancer and their families and includes both palliative care programs in acute care facilities and hospice care programs in the community. Oncologists are often involved in the management of various acute and chronic treatment-related adverse effects and may involve other disciplines on a referral basis (e.g., pulmonary medicine for interstitial lung disease). Survivorship programs focus on providing care to cancer-free individuals.
Supportive care

actively involved in research in supportive care and also educating other professionals in supportive care issues.

When making a ‘supportive care’ referral, it is important to identify the specific supportive care needs of the individual to decide on the specific ‘supportive care’ service. As an analogy, when we refer a patient to oncology for treatment of cancer, it is crucial to learn about the stage of disease before deciding whether the patient should be seen by surgical, medical, or radiation oncology. Similarly, a good understanding of a patient’s supportive care need and the specific roles of each supportive care program would allow us to identify the appropriate supportive care service for referral. For a patient with advanced cancer who presents with multiple symptom concerns, referral to a palliative care program may be the most appropriate. In contrast, a patient who presents with lymphedema as the main concern after mastectomy and axillary lymph node dissection for localized breast cancer may benefit from a referral to multidisciplinary lymphedema clinic.

RESEARCH IMPLICATIONS: THE ELUSIVE ‘SUPPORTIVE CARE’ AS AN INTERVENTION

The theme of this issue of Current Opinion in Oncology is ‘supportive care.’ This label is appropriate because it covers a variety of supportive care topics, including treatment of cancer effects of cancer therapies, cachexia for patients with advanced cancer, and palliative sedation for cancer patients near the end-of-life.

However, the term ‘supportive care’ is not often used with precision in the medical literature. In randomized controlled trials, the control arm is sometimes labeled as ‘supportive care’ or ‘best supportive care’ (Table 2) [28–35]. In many of these studies, ‘supportive care’ entails standard care provided by the oncology team, with variable levels of primary supportive care delivered by oncologists and may or may not include referral to secondary supportive care services [11**,36]. Ironically, ‘best supportive care’ may sometimes be used to describe limited supportive care [15].

The use of the term ‘supportive care’ to describe an intervention (active or control) is thus ambiguous at best and could potentially confuse the readers. Multiple groups have highlighted the potential for misuse of this term [15,37,38]. At the minimum, studies that include a ‘supportive care’ arm should include specific details on what it entails. If only primary supportive care was provided, the term ‘standard oncologic care’ may be more appropriate than ‘supportive care’ to describe the study arm.

Clinical trials should ideally build on the high standard of care. Given the growing evidence to support improved outcomes with various

<table>
<thead>
<tr>
<th>Table 2. Examples of definitions of ‘supportive care’ and ‘best supportive care’ in clinical trials</th>
</tr>
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<tbody>
<tr>
<td><strong>Publication</strong></td>
</tr>
<tr>
<td>Rapp et al. [28]</td>
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<td>Ganz et al. [29]</td>
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<td>Cartei et al. [30]</td>
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<td>Bredin et al. [31]</td>
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<td>Anderson et al. [32]</td>
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<td>Rao et al. [33]</td>
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<td>Van Cutsem et al. [34]</td>
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<td>Jassem et al. [35]</td>
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</tbody>
</table>
Definition of supportive care

Hui

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

■ of special interest
■■ of outstanding interest


This study highlights the relative frequency of occurrence and the lack of definitional clarity for many key terms such in supportive and palliative oncology.


A comprehensive systematic review on existing definitions for multiple key terms in supportive care. The findings inform a unifying conceptual model for these terms.


supportive care interventions, it would be advisable for investigators to ensure patients are receiving a consistently high level of supportive care regardless of which treatment arm they are assigned to. For instance, randomized controlled trials examining the effectiveness of a novel cancer treatment in patients with metastatic nonsmall cell lung cancer may consider involving routine referral to palliative care in both study arms (i.e. cancer treatment and palliative care versus palliative care alone).

CONCLUSION

Over the past decade, there has been a heightened awareness of the importance of supportive care in cancer patients, and growing literature to support its role in enhancing patient outcomes. Our recent systematic reviews led to the development of a conceptual model, which supports a broad definition for supportive care: ‘the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or followup phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement.’

Supportive care can be classified as primary, secondary, and tertiary based on the level of specialization. In the clinical setting, clinicians need to properly identify the unique supportive care needs of each patient and make the referral to the appropriate supportive care service. For patients with advanced cancer, palliative care teams can often address the multidimensional care needs. In the clinical trial setting, investigators should ensure that all patients receive the highest standard of care, ideally with regular involvement of secondary supportive care services. Study arms with only primary supportive care delivered by the oncology team may be more appropriately labeled as ‘standard oncologic care.’

Finally, we urgently need a consensus definition for supportive care that is universally accepted. Until then, this term should be clearly defined or cited whenever it is used.

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Conflicts of interest

There are no conflicts of interest.
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