

# Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement

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**Abstract** This position paper, written on behalf of the MASCC Psychosocial Study Group, reviews the most common psychosocial concerns and needs of cancer patients during all phases of the cancer continuum, from diagnosis to death or survivorship. Developments in psychosocial care at both individual and systems levels are surveyed and summarized, along with gaps in knowledge and research and needed improvements in the dissemination and application of acquired knowledge and expertise. The roles of culture, spirituality, and religion as

part of psychosocial care are reviewed, along with families' and caregivers' specific psychosocial concerns and needs, and areas of needed psychosocial interventions in supportive cancer care. Deficits in recognizing and meeting patients' psychosocial needs at the system level are examined, and international guidelines and models of psychosocial care are reviewed, including their potential applications to local contexts. The paper calls for a shift to a new paradigm of care through adoption of an integrated approach to identify and meet the psychosocial needs of cancer patients and survivors as part of supportive care worldwide.

**Keywords** Cancer · Supportive care · Patients' psychosocial concerns · Unmet psychosocial needs · Psychosocial interventions

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## Background: psychosocial study group and MASCC

The Multinational Association of Supportive Care in Cancer (MASCC) is an international, multidisciplinary organization dedicated to research and education in all measures of supportive care for patients with cancer, regardless of the stage of disease. MASCC was established in the late 1980s, when a number of visionary medical professionals working independently in Europe and North America became interested in the concept of supportive care for cancer patients. From its inception, MASCC has welcomed the membership of all cancer professionals, making it not only an international but also a multidisciplinary association dedicated to supportive care.

Supportive care in cancer is defined as the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the

continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship, and end-of-life care are integral to supportive care. Through its official journal, *Supportive Care in Cancer*, first published in 1993 [1] and through annual international symposia, MASSCC has fostered the development of a culture of supportive care tailored to the needs and resources of different local contexts, emphasizing both evidence-based findings and holistic care. New measurement tools, such as the MASCC Score for febrile neutropenia and the antiemetic guidelines, have quickly become standards in oncology [2–4].

The goals and objectives of MASCC are achieved through the projects of its 17 study groups. The Psychosocial Study Group, launched in the late 1990s, established its mission and plans in 2004, when the group's leadership became involved in research and teaching on the ethical, psychological, and social aspects of supportive care through the entire cancer trajectory [5]. Now, the group is committed to bringing these key aspects of supportive care to the forefront by reviewing and summarizing international knowledge and expertise in psychosocial care and calling MASCC members to establish and promote psychosocial care as an integral component of supportive care in cancer.

### Psychosocial concerns in cancer patients: met and unmet needs

The basic psychosocial issues of all cancer patients can be classified according to concrete and practical categories. These should not be considered as fixed, since patients' psychosocial concerns and needs change over time, as their cancer trajectory evolves from diagnosis toward progression and death, or toward remission and survivorship (Table 1). The Institute of Medicine (IOM) recently issued a report entitled "Cancer for the whole patient: meeting psychosocial health needs" [6]. The document states that the psychosocial dimension, including appropriate assessment and interventions, must become an integral part of routine cancer care for all patients. While supportive care during the treatment phase has improved considerably during the last 20 years, and its

scope and intervention modalities are now well defined, the parameters of adequate supportive care along the entire cancer continuum have not been fully established. Empirical research, however, clearly demonstrates that cancer affects all aspects of the patient's life and is a disease of the entire family. As a consequence, medical and psychosocial issues are inextricably intertwined at all stages of cancer care [6]. In this paper, we review what we know and where we stand with regard to how to integrate the psychosocial dimension into supportive care from the time of diagnosis to that of relapse or death, as well as through the various "seasons of survival" [7].

As the subject has multiple dimensions, we elected to focus on the psychosocial concerns and needs of cancer survivors, patients at advanced stages of cancer and end of life, and of family and caregivers. We then analyze the spiritual and cultural dimensions of supportive care in cancer, before discussing guidelines and models of psychosocial evaluation and intervention in supportive cancer care.

### Psychosocial concerns and needs of cancer survivors

Approximately 11 million people in the USA, and 25 million people worldwide, live with a past or present diagnosis of cancer [8]. Cancer survivorship is defined as extending from diagnosis till death [9]. When patients are diagnosed and treatment is initiated, the primary goal is therapeutic, and psychological, emotional, and social factors tend to become secondary to immediate treatment decision-making. Research, however, has shown that most medical and psychosocial issues of survivorship begin at the time of diagnosis and treatment [10]. Hence, emotional and psychosocial dimensions should be addressed in initial encounters with patients [11, 12]. The National Cancer Institute (NCI) Office of Cancer Survivorship recommends that oncology professionals acquire specific education on both immediate treatment decisions and long-term sequelae of cancer treatments [13] (Table 2).

Consideration of survivorship as an essential dimension of the cancer trajectory starting with diagnosis of any cancer is a relatively new concept, and a review of cancer control strategies and of clinical practice guidelines on follow-up

**Table 1** Common cancer patients' psychosocial concerns and needs

1. Treatment and follow-up care for psychosocial distress
2. Financial assistance
3. Child care assistance
4. Follow-up care beyond treatment to survivorship
5. Emotional and spiritual concerns
6. Special needs in end-of-life care
7. Special care for elderly cancer patients
8. Family and caregiver support, including psychological distress and social needs
9. Follow-up care for families during and after grieving

**Table 2** Psychosocial factors affecting quality of life of cancer survivors

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1. Fear of relapse
  2. Body image consciousness, awareness of “being different”
  2. Concerns about sexuality and fertility
  3. Stigmatization and discrimination
  3. Employment, insurance
  4. Meeting family’s expectations
  5. Reassimilating with their peer groups
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care reveals only a few studies that address the complexities of cancer survivorship [14]. In the US literature, survivorship begins at diagnosis and includes the re-entry phase, the transition from the treatment to the post-treatment stages [9, 12]. In many other countries, however, survivorship is considered to start 3 to 5 years after the completion of treatment [14, 15]. Despite these important differences in definition, which can affect both estimates of and approaches to survivorship, survivorship is an emerging reality worldwide. In 2005, the World Health Organization (WHO) issued two reports, the first on aging of the worldwide population and the second on cancer as a health care priority in both developed and developing countries [16, 17]. The WHO stresses that, due to global population aging and increased curability of cancer in developing countries, the number of cancer patients and survivors is rapidly increasing worldwide. Experts in supportive care are key players in addressing the medical and psychosocial issues associated with survivorship in different local contexts and to help in bridging the gap in the delivery of supportive care to cancer survivors between developed and developing countries [18, 19].

The IOM Report, “Lost in Transition,” recognizes that cancer survivorship in the US presents an enormous challenge to the individual patients’ health care team and to health care systems at large, and offers practical strategies for overcoming individual and system barriers to properly address cancer survivors’ needs, including that of giving proper information about survivorship issues [9]. The experience of survivorship is different for each cancer patient and is related to many individual and societal variables, including age, gender, socioeconomic status, family support, community resources, and different cultural views of the meaning of cancer and disability. Many survivors adapt to their post-treatment situations and continue to successfully engage in productive or otherwise meaningful activities. Others struggle with persistent psychological vulnerability or physical disability. Others still experience difficulties in resuming their jobs and may be stigmatized or, at times, openly discriminated against [20–22]. By promoting survivors’ emotional and social adjustments, supportive care experts assist in identifying

resources and overcoming barriers among diverse populations [23, 24].

The more cancer professionals seek to understand patients’ experience of their illness and survivorship, the greater will be their ability to match those needs with the appropriate psychosocial interventions and support programs. According to the IOM and NCI reports, the immediate goals for the oncology community are to establish a consensus definition of cancer survivorship, to identify common medical, psychological, and social sequelae of cancer diagnosis and treatment, to provide continuity in treatment and care of survivors, and to develop models for evidence-based research with diverse populations [6, 9, 13]. Models and standards of care include preventive strategies and detailed recommendation plans for follow-up care based on the specific needs of individual cancer survivors and the local resources of each community [25–30].

### **Psychosocial concerns and needs of cancer patients at advanced stages and at the end of life**

Under the influence of palliative and supportive care experts, major changes in oncology professionals’ attitudes and behaviors surrounding patient death and dying have occurred [31]. As oncology professionals pay increasing attention to medical and psychosocial end-of-life issues, they address the patient experience of terminal illness in a multidisciplinary, multidimensional, patient- and family-centered way [32, 33]. Supportive care experts help alleviate physical, psychological and spiritual suffering, offering competent compassionate care during the dying and grieving process. They can also act as facilitators and coordinators for patients and families in navigating health care systems and in finding available palliative and hospice care services [34]. Cancer patients’ experiences in dying need to be understood and integrated within the context of their cultural values and community, which entail different meanings, life narratives, and spiritual and religious elements [34]. Supportive and palliative care specialists most often work together as part of teams where all dimensions of the person are addressed with utmost respect for the individual preferences and vulnerabilities of the dying patient and his or her family and loved ones [34–36]. Across different cultures, in fact, cancer patients’ families assume the role and the burden of providing care toward the end of the patient’s life. Functional interactions among families, patients, and oncology professionals are, therefore, essential. Equally important is to consider the emotional, social, and financial tolls that caregiving takes on family members and to assess the quality of life of caregivers and provide them with psychological and social assistance [37–39].

### Psychosocial concerns and needs of families

Every person is born into a family and dies within a fantasized or real family. The experience of chronic illness is inseparable from the family life history and is embedded within cultural, religious, and historical contexts that shape families' appraisal and value orientations towards cancer. Family has been described as the basic social and ethical unit of cancer care, since all confrontations with patients' illnesses and with their death and dying belong to the moral realm of family boundaries [40, 41].

The threat that cancer poses to the family can be understood in light of how different members, individually and as a whole, construct and share meanings about specific stressful situations, their identity as a family, and their view of the world [42, 43]. Neither patients nor their families can ever return to a pre-illness situation [40]. Successful coping with the separations and losses that accompany cancer patients in their illness trajectory is dependent on solid and mature family relationships. Providing emotional or instrumental support to cancer patients' families during the entire illness is based on a thorough assessment of their cohesiveness, mutuality, flexibility, and shared needs [44]. Supportive care professionals can help to identify adaptive, functional, and non-adaptive family coping mechanisms, as well as family conflicts. Both patients and family members can benefit from various forms of psychological intervention [45, 46]. When a trained psychologist or supportive care professional is available, this goal can be attained even in situations with limited resources.

### Psychosocial concerns and needs of caregivers

As the number of cancer patients and survivors of all ages increases, the role of caregivers grows as well. Most caregiving is provided by families and friends, often taking a major toll on them in emotional and economic terms [41]. Caregiving to cancer patients can be demanding, as it involves dealing with the sudden onset of cancer, its potentially life-threatening nature, and varying degrees of need for supportive care, which may be sporadic at the onset, but tends to become progressively more intense as the illness evolves [47]. Most cancer caregivers worldwide are women, although the number of male caregivers is growing especially for older patients [48]. Men tend to feel less prepared for caregiving roles and to encounter more difficulties than women with regard to maintaining their own employment, being accepted by colleagues and friends, being respected by nursing home staff, and finding social resources. Empirical studies demonstrate that, regardless of gender, age, and ethnicity, caregivers are at risk for major stress, anxiety, and

depression, and are vulnerable to possible physical and financial repercussions [49].

Supportive care specialists can assist in developing effective strategies for family and friends to ask for help, enjoy aspects of their own lives without feeling guilty, recognize signs of stress and depression, and seek professional help when needed [50]. Supportive cancer care should include making caregivers aware of their country's laws and regulations in matters of employment and leaves of absences and of available support structures in their communities [50]. Finally, new aspects of caregiving are emerging with regard to the long-term psychosocial repercussions on the families of long-term cancer survivors. These may range from psychological distress to financial issues to different degrees of stigmatization or discrimination [51].

### The spiritual dimension of supportive care in cancer

Spirituality is increasingly recognized as an essential dimension of cancer patients' paths toward healing or dying. Patients may express their spiritual concerns at all stages of their illness and survivorship, and especially at the end of life. Spirituality in oncology must be addressed with utmost respect for individual and cultural differences in patients' preferences, beliefs, and rhythms [52–55]. Spirituality relates to culture and religion; together, they influence perceptions of health and illness and yet have separate spheres of influence and action [52, 56]. Religion encompasses the congregational aspects and formal ways to express one's beliefs. Spirituality involves broader dimensions and is based on personal authenticity, irrespective of sources of authority and rituals of worship [52, 57].

Different tools for assessing patients' spiritual needs in the clinical setting have been developed, including self-rating instruments [58–63]. A basic spiritual history takes only a few minutes, but may open a channel of future communication between the cancer patient and oncology professionals [64]. In the USA, the Joint Commission for the Accreditation of Healthcare Organizations mandates a basic written spiritual assessment for patients admitted to acute care facilities, nursing homes, or home health agencies [65]. Surveys show that many US patients, even when not religious, feel it is appropriate for physicians and other team members to inquire about their spirituality, while other cancer patients prefer to confide in pastoral care [66, 67]. In western countries in general, some cancer patients may ask their oncologists to pray together with them, yet most physicians prefer to leave teams of professional spiritual counselors, trained in acting as advisors for patients of western and eastern systems of beliefs, in charge of patients' spiritual and religious concerns [68–70]. Up to now, there are limited data from eastern countries, but

cultural variation in matters of spirituality and religion is likely to be present and should be taken into account before making generalizations or assumptions based only on the experiences of western patients and physicians.

Within the context of an established relationship, it is easier to meet patients' spiritual needs through progressive steps, from establishing an empathic connection with patients or their families up to engaging with them in spiritual discussions or referring and introducing them to members of a spiritual team, when available [71]. Spiritual teams are becoming more common in western countries, and generally consist of hospital chaplains or spiritual advisors trained to address patients' spirituality, in conjunction with, or separate from, their religious faith, along with other members of the clergy, cancer survivors, volunteers, and interested oncology professionals. Dedicated physical spaces where patients' spiritual concerns can be discussed and addressed separately from clinical issues are also being established in some hospitals [72].

Given the inherent asymmetry of the patient–doctor relationship, it is especially important for oncology and supportive care professionals to be aware of the difficulties and potential risks of acting as spiritual advisors. This role requires specific education and training that are not yet provided in most medical schools [73]. Yet, in most clinical practices worldwide, physicians and nurses are often called to address the spiritual concerns of their patients. Education and training in basic communication skills is required to enable all oncology professionals to respond appropriately to their patients' questions, even in the absence of specific training in dealing with spiritual issues, admitting their ignorance or uncertainty when needed, without being evasive or judgmental. Teaching and training in communication is still missing from the curriculum of many medical schools and oncology programs. It should be a priority to assure the acquisition of communication skills by those who will care for cancer patients [74, 75]. Furthermore, oncologists and supportive care professionals should be taught how to recognize those patients' spiritual claims that may mask denial or unresolved conflicts, requiring patient referral for proper counseling [40, 55, 71].

### The cultural dimension of supportive care in cancer

Culture is the sum of the integrated patterns of knowledge, beliefs, and behaviors of a given community, through the integration of many contributing factors that include, but also go beyond, ethnic and geographic boundaries, age, gender, religion, and educational level [76–78]. Culture influences values and lifestyle choices, including those related to health matters. Cross-cultural differences may

have an impact on cancer care along its continuum, from prevention, screening, and early detection to treatment access and response, rehabilitation, and palliative care, and finally to end-of-life care or survivorship [73, 79].

Cultures are responsive, adaptive, and evolving especially in multiethnic societies where acculturation and assimilation take place at varying paces and degrees with regard to health attitudes and practices [77]. Certain cultural beliefs or behaviors related to health may be judged as dysfunctional when observed from the perspective of western medicine [76, 77, 79, 80]. The goal in oncology practice is to develop individual and institutional sensitivity in order to be able to understand and respond appropriately to different health values and coping strategies of diverse cultural communities. For example, family- and community-centered cultures value and encourage the protective role that families assume when a patient is diagnosed, shielding him or her from painful truths about their diagnosis and prognosis. In cultures centered on individuals' rights, on the other hand, full disclosure of medical information is deemed necessary to allow cancer patients to make autonomous decisions about their treatment and end-of-life choices [81–83]. With sensitivity to the different health values and attitudes of each patient and cultural group, it is possible to negotiate between discordant cultural views among oncology professionals, patients, and families in order to achieve a common therapeutic goal [84].

Cross-cultural differences play an equally important role in communicating and planning psychosocial interventions for cancer patients. Formal teaching and training of patient-centered approaches to cross-cultural care, based on assessing core cross-cultural issues, exploring meaning of illness to patient, determining patient's lived social context, and negotiating adherence to recommendations and treatments, is being implemented in many countries [76, 77, 85]. To be effective, individual cultural competence must be accompanied by the establishment of culturally competent health care systems with the capacity to adapt their services to meet the culturally unique needs of their patients, also through the involvement of their different communities [85, 86].

### Guidelines and models of psychosocial evaluation and intervention in supportive cancer care

Despite a wealth of recent publications on how to identify and address the psychosocial needs of cancer patients in different contexts, only a few official guidelines have been published. The presence of cross-cultural differences that affect patients' and families' health beliefs and values, and of a wide range of ethical norms and health policies in different countries, make it impossible to suggest implementation of a single therapeutic model. Rather, it is

necessary to evaluate which model could be more easily absorbed and integrated in diverse local realities across the world, taking into account the scarcity of health resources of most non-industrialized countries.

The “Tiered” model is an example of an integrated multidimensional approach to cancer patients, articulated within the community [87]. This intervention model provides a framework for implementing psychosocial care through a community-based approach that tailors the level of intervention to the degree of patients’ and families’ psychosocial distress, integrating different services and sectors within each community. In order to adapt the model to a given setting, oncology and supportive care professionals need to identify not only the needs of each patient but also the services provided by their communities [87].

While it is impossible to “Xerox” models of care, we can nevertheless reframe successful care programs within the limitations of the local resources and manpower of each community. For example, in many western and non-western clinical contexts, mental health teams are integrated in psychosocial units and deliver a comprehensive model of family–patient–community care that takes into account social, cultural, and religious factors and is based on evidence-based outcomes research, manpower, and available resources. In many small communities and in poverty settings, schools, places of prayer, social settings for elders, and community resources for youth can be viable channels of information about psychological support and effective instruments for its delivery. Physicians and nurses together are an integral part of any psychosocial care for cancer patients. Case discussions should never be limited to the evaluation of patients’ treatment progress, but rather always should include a wider evaluation of the quality of patients’ and families’ life. This task requires sharing knowledge and specific expertise among all cancer professionals.

### Conclusions and future perspectives

Though much progress has been made in regard to psychosocial care for cancer patients, there is still no truly comprehensive and integrated approach to all the issues that have been identified, studied, and sometimes applied in the clinical setting. This lack of integration at the clinical level

is mirrored in the lack of an integrated approach at policy, practice, institutional, and disciplinary levels. This MASCC Psychosocial Study Group Position Paper has reviewed and summarized the main psychosocial concerns and needs of cancer patients, as well as structural and systemic deficiencies present in industrialized countries. It is intended as a call to action for all MASCC international members to work together to overcome existing institutional and structural barriers within different communities and health care systems in order to provide adequate psychosocial support to cancer patients, survivors, and their families. To achieve this ambitious goal, improvements are needed in several aspects of psychosocial care: (1) the role of culture, spirituality, religion, families, and caregivers still needs to be better understood, defined, and be subjected to rigorous empirical research; (2) institutions and individual professionals must commit to proper training of oncology professionals and to the establishment of interdisciplinary teams, including mental health and rehabilitation specialists; (3) professional organizations should gather information on legal and financial issues that affect patients’ and families’ psychosocial well-being in all patients’ groups, including minority and underprivileged ones; (4) a new paradigm of supportive care that addresses psychosocial issues from diagnosis through treatment and post-treatment phases, up to end-of-life or long-term survivorship, must be implemented; (5) existing gaps in cancer treatment and psychosocial care across different countries and practice settings must be identified and brought to closure.

In order to achieve these goals, MASCC should link with other specialty organizations that have implemented good clinical practices of psychosocial care, including WHO, UICC, ASCO, IPOS, ONS, and others that are committed to the integration of multidimensional and multi-professional expertise in providing comprehensive and culturally sensitive psychosocial care for cancer patients and survivors [88, 89]. The International Psycho Oncology Society (IPOS), for example, has developed and disseminated several multidimensional approaches to address psychosocial issues of cancer patients and their families in different cultural settings. The International Multilingual Core Curriculum in Psycho-Oncology, already translated into nine different languages, is an example of an on-line teaching instrument focused on ten basic aspects of psycho-oncology, which can be accessed easily [90]. The Australian

**Table 3** Psychosocial dimensions of supportive care in cancer requiring further research

1. Assessment tools to elicit concerns and evaluate psychosocial needs of cancer patients that can be met by supportive care experts
2. Specific strategies to support spouses, families, and caregivers who assist cancer patients facing substantial emotional and financial costs
3. Psychosocial interventions for culturally diverse patients and families
4. Education of supportive cancer care experts and of patients and their families
5. Funding for research and intervention in providing psychosocial support to cancer patients and families at all stages of their illness, including survivorship

guidelines for psychosocial care are a most effective tool for oncologists, as are the ONS guidelines for nurses working in the oncology field [88, 91]. Such tested approaches can be adapted by local communities, according to their cultural needs and resources.

The psychosocial dimensions of supportive care most in need of our urgent attention in clinical practice are summarized in Table 3. Supportive care specialists should familiarize themselves with those aspects for which empirical research and interventions strategies have already been developed, and be prepared to refer patients for specialized psychosocial interventions when needed [6, 13, 92]. Counseling of patients can be complemented by the distribution of educational and self-help material or professional referral to reliable Internet sources [93].

The economic impact of psychosocial interventions also must be considered. At present, there are no standards for evaluating cost effectiveness of psychosocial end points in interventional supportive trials. For example, educational videos seem to be a cost-effective way to improve transition in breast cancer survivors worldwide, but they have not been shown to be effective for other cancers [94]. Furthermore, outcome measures are applied to evaluate intermediate and long-term cost effectiveness, and vary on the basis of their clinical or subjective end point. Studies of fatigue and low energy, which affect patients' emotional and psychosocial well-being, show that positive intermediate outcomes significantly improve individual and family productivity [28].

The 2008 World Cancer Declaration includes some important psychosocial aspects that are integral to the provision of basic cancer care worldwide [89]. Yet many of the medical, psychological, and psychosocial needs of cancer patients and survivors remain unmet in contemporary oncologic care, despite the active involvement medical societies and of patient advocacy [95]. Identifying and addressing patients' and families' psychosocial needs according to the multiple variables that affect them, such as type and stage of cancer, age at diagnosis, gender, and socioeconomic and educational status of affected patients and survivors, and according to different local conditions and resources, is a challenging task that requires the full commitment of individual professionals dedicated to supportive cancer care, as well as that of our organization. MASCC has demonstrated the capability to change oncology practices worldwide toward more holistic, patient-centered care through the development of new strategies in supportive care and their implementation worldwide [2–4]. As a large international multidisciplinary organization, MASCC can also have an impact in making cancer patients' psychosocial concerns and needs a priority at institutional and policy-making levels across countries and health systems.

## References

- Senn HJ (1993) How “supportive” is yet another international oncology journal? *Supp Care Cancer*, 1:1
- Klastersky J, Paesmans M, Rubenstein EB et al (2000) The multinational association for supportive care in cancer risk index: a multinational scoring system for identifying low-risk febrile neutropenic cancer patients. *J Clin Oncol* 18:3038–3051
- Uys A, Rapoport BL, Anderson R (2004) Febrile neutropenia: a prospective study to validate the Multinational Association of Supportive Care of Cancer (MASCC) risk-index score. *Support Care Cancer* 12:555–560
- Gralla RJ, Roila F, Tonato M (2005) The 2004 Perugia Antiemetic Consensus Guideline process: methods, procedures, and participants. *Supp Care Cancer* 13:77–79
- Holland J, Weiss T (2008) The new standard of quality cancer care: integrating the psychosocial aspects in routine cancer from diagnosis through survivorship. *Cancer J* 14:425–428
- Institute of Medicine (2007) Cancer care for the whole patient. Meeting psychosocial health needs. The National Academies Press, Washington, DC
- Mullan F (1985) Seasons of survival: reflections of a physician with cancer. *N Engl J Med* 313:270–273
- Ries L, Krapcho M, Stinchcomb DG et al (eds) (2008) SEER Cancer Statistics Review, 1975–2005. National Cancer Institute, Bethesda, MD
- Institute of Medicine (2005) From cancer patient to cancer survivor: lost in transition. In Hewitt M, Greenfield S, and Stovall E (eds) Committee on Cancer Survivorship: improving care and quality of life. The National Academies Press, Washington, DC
- Ganz PA (ed) (2007) Cancer survivorship: today and tomorrow. Springer, New York
- Surbone A, Peccatori F (2006) Unmet needs of cancer survivors: supportive care's new challenge. *Supp Care Cancer* 15:397–399 (Editorial)
- Ganz PA, Desmond KA, Leedham B et al (2002) Quality of life in long-term, disease-free survivors of breast cancer: a follow-up study. *J Natl Cancer Inst* 94:39–49
- US Department of Health and Human Services. National Institutes of Health. The NCI Strategic Plan for Leading the Nation to Eliminate the Suffering and Death due to Cancer. 2007 accessible at <http://strategicplan.nci.nih.gov/>
- Grunfeld E (2006) Looking beyond survival: how are we looking at survivorship? *J Clin Oncol* 24:5166–5169
- Kahn N (2007) Long-term survivors of adult cancers and uptake of primary health services: a systematic review. *Eur J Cancer* 44:195–204
- World Health Organization (2005) Fifty-eight world Health Assembly. International plan of action on ageing: report on implementation. Geneva: World Health Organization, Document A58/19
- World Health Organization (2005) Resolution on Cancer Control WHA58.22. Geneva: World Health Organization, Document A58/22
- Kaplan M (2008) Cancer survivorship: meeting psychosocial needs. *Clin J Oncol Nurs* 12:989–992
- Last B, Grootenhuis M, Eiser C (2005) International comparison of contributions to psychosocial research on survivors of childhood cancer: past and future considerations. *J Pediat Psychol* 30:99–113
- Short PF, Vargo MM (2006) Responding to employment concerns of cancer survivors. *J Clin Oncol* 32:5138–5141
- deBoer AGEM, Taskila T et al (2009) Cancer survivors and unemployment. *JAMA* 301:753–762
- Avis NE, Crawford S, Manuel J (2004) Psychosocial problems among younger women with breast cancer. *Psycho-Oncol* 13:295–308
- Ashing-Giwa KT, Padilla G, Tejero J et al (2004) Understanding the breast cancer experience of women: a qualitative study of

- African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncol* 13:408–428
24. Guidry JJ, Torrence W, Herbelin S (2005) Closing the divide: diverse populations and cancer survivorship. *Cancer* 104:2577–2583
  25. Tesauro GM, Rowland JH, Lustig C (2002) Survivorship resources for post-treatment cancer survivors. *Cancer Pract* 10:277–283
  26. Tonorezos ES, Oeffinger KC (2008) Survivorship after childhood, adolescent and young adult cancer. *Cancer J* 14:388–395
  27. Zebrack B (2009) Information and service needs for young adult cancer survivors. *Supp Care Cancer* 17:349–357
  28. Chirikos TN, Russell-Jacobs A, Cantor AB (2002) Indirect economic effects of long-term breast cancer survival. *Cancer Pract* 10:248–255
  29. Frazier LM, Miller VA, Horbelt DV et al (2009) Employment and quality of survivorship among women with cancer: domains not captured by quality of life instruments. *Cancer Control* 16:57–65
  30. Mikkelsen T, Sondergaard J, Sokolowski I, Jensen A, Olesen F (2009) Cancer survivors' rehabilitation needs in a primary health care context. *Fam Pract* 26:221–230
  31. Armstrong D (1987) Silence and truth in death and dying. *Social Science Med* 24:651–657
  32. Della Santina CH, Bernstein RH (2004) Whole patient assessment, goal planning, and inflection points: achieving quality end-of-life care. *Clinic Geriatric Med* 20:595–620
  33. Parker SH, Clayton JH, Hancok J et al (2007) A systematic review of prognostic/end of life communication with adults of a life limited illness. *J Pain Symptom Manag* 34:81–93
  34. Crawley L, Kagawa Singer M, Rutman LE (2007) Racial, cultural, and ethnic factors affecting the quality of end-of-life care in California: Supplemental Materials. California Health Care Foundation
  35. Pessin H, Galietta M, Nelson CJ, Brescia R, Rosenfeld B, Breitbart W (2008) Burden and benefit of psychosocial research at the end of life. *J Palliat Med* 11:627–632
  36. Rousseau P (2003) Death denial. *J Clin Oncol* 21:52–53
  37. Taboada P, Bruera E (2001) Ethical decision-making on communication in palliative cancer care: a personalist approach. *Supp Care Cancer* 9:335–343
  38. Mook E, Chan F, Chan V et al (2003) Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nursing* 26:267–275
  39. Cohen R, Leis AM, Kuhl D, Charbonneau C, Ritvo P, Ashbury FD (2006) QOLLI-F: measuring family carer quality of life. *Palliat Med* 20:755–767
  40. Baider L, Cooper CL, Kaplan De-Nour A (eds) (2000) *Cancer and the family* (2nd revised edn). Wiley, London
  41. Boszormenyi-Nagy I, Ulrich DN (1981) Contextual family therapy. In: Gurman AS, Knistern D (eds) *Handbook of family therapy*. Brunner-Mazel, New York, pp 159–186
  42. McLean LM, Jones JM, Rydall AC, Walsh A, Esplen MJ, Zimmermann C, Rodin GM (2008) A couples intervention for patients facing advanced cancer and their spouses. *Psycho-Oncol* 17:1152–1156
  43. Baider L, Ever-Hadani P, Goldzweig G, Wygoda M, Peretz T (2003) Is perceived family support a relevant variable in psychological distress? A sample of prostate and breast cancer couples. *J Psychosom Res* 55:1–8
  44. Goldzweig G, Hubert A, Walach N, Brenner B, Perry S, Andritsch E, Baider L (2009) Gender and psychological distress among middle- and older-aged colorectal cancer patients and their spouses: an unexpected outcome. *Crit Rev Oncol Hematol* 70:71–82
  45. Manne S, Ostroff J, Sherman M, Heyman RE, Ross S, Fox K (2004) Couples' support-related communication, psychological distress, and relationship satisfaction among women with early-stage breast cancer. *J Consult Clin Psychol* 72(4):660–670
  46. Hodges LJ, Humphris GM, Macfarlane G (2005) A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med* 60:1–12
  47. Kim Y, Schultz R (2008) Family caregivers' strains. *J Aging Health* 20(5):483–503
  48. Surbone A (2003) The difficult task of family care giving in oncology: exactly which roles do autonomy and gender play? *Support Care Cancer* 11:617–619
  49. Rhee YS, Yun YH, Park S et al (2008) Depression in family caregivers of cancer patients: the feeling of burden as a predictor of depression. *J Clin Oncol* 26:5890–5895
  50. PLWC Editorial Board. How care givers can take care of themselves. July 2005, available at [www.cancer.net/](http://www.cancer.net/)
  51. Lewis F (2006) The effects of survivorship on families and caregivers. *Cancer Nurs* 29(2 Suppl):20–21, 23–25
  52. Wright M (2002) The essence of spiritual care: a phenomenological enquiry. *Palliat Med* 16:125–132
  53. Surbone A (1993) The information to the cancer patient: psychosocial and spiritual implications. *Support Care Cancer* 1:89–91
  54. Astrow AB, Wexler A, Texeira K, Kai He M, Sulmasy DP (2007) Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? *J Clin Oncol* 25:5753–5757
  55. Mc Clain CS, Rosenfeld B, Breitbart W (2003) Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet* 361:1603–1607
  56. Surbone A, Baider L (2009) The spiritual dimension of cancer care. *Crit Rev Oncol Haematol*, Epub ahead of print, April 28<sup>th</sup>
  57. Eckersley RM (2007) Culture, spirituality, religion and health: looking at the big picture. *MJA* 186:S54–S56
  58. Maugans TA (1996) The SPIRITual history. *Arch Fam Med* 5:11–16
  59. Hatch RL, Burg MA, Baberhaus DS, Hellmich LK (1998) The spiritual involvement and beliefs scale. Development and testing of a new instrument. *J Fam Pract* 46:476–486
  60. Holland JC, Kash KM, Passik KS, Sison A, Lederberg M et al (1998) A brief spiritual beliefs inventory for use in quality of life research in life-threatening illness (SBI). *Psycho-Oncology* 7:460–469
  61. Baider L, Holland J, De-Nour A (2001) The System of Belief Inventory (SBI-15R): a validation of study in Israel. *Psycho-Oncol* 10:534–541
  62. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D (2002) Measuring spiritual well-being in people with cancer: The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp). *Ann Behav Med* 24:49–58
  63. Puchalski CM (2002) Spirituality and end-of-life care: a time for listening and caring. *J Pall Med* 5:289–294
  64. Kristeller JL, Zumbun CS, Schilling RF (1999) "I would if I could": how oncologists and oncology nurses address spiritual distress in cancer patients. *Psycho-Oncology* 8:451–458
  65. Spiritual Assessment. Available at <http://www.jointcommission.org>
  66. Ehman JM, Ott B, Short TH, Ciampa RC, Hansen-Flaschen J (1999) Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Arch Intern Med* 159:1803–1806
  67. Sloan RP, Bagiella E, VandeCreek L et al (2000) Should physicians prescribe religious activities? *N Engl J Med* 342:1913–1916
  68. Anandarajah G, Mennillo R (2007) Curbside consultation. Responding to a patient's request to pray. *Am Fam Physician* 76:133–134
  69. Monroe MH, Bynum D, Susi B et al (2003) Primary care physician preferences regarding spiritual behavior in medical practice. *Arch Intern Med* 163:2751–2756
  70. Koenig HG (2007) *Spirituality in patient care: why, how, when and what*. Templeton Foundation, West Conshohocken



71. Sulmasy DP (2006) Spiritual issues in the care of dying patients. “...It’s okay between me and God”. *JAMA* 296:1385–1392
72. Milstein JM (2008) Introducing spirituality in medical care. Transition from hopelessness to wholeness. *JAMA* 299:2440–2441
73. Russell-Searight H, Gafford J (2005) Cultural diversity at the end of life: issues and guidelines for family physicians. *Am Fam Phys* 71:515–522
74. Fallowfield L, Jenkins V (1999) Effective communication skills are the key to good cancer care. *Eur J Cancer* 35:1592–1597
75. Back AL, Arnold RM, Baile WF et al (2009) Faculty development to change the paradigm of communication skills teaching in oncology. *J Clin Oncol* 27:1137–1141
76. Association of American Medical Colleges. Medical Education and Cultural Competence: A Strategy to Eliminate Racial and Ethnic Disparities in Health Care. Supported by The Commonwealth Fund. Division of Diversity Policy and Programs 2005. Accessible at [www.AAMC.org](http://www.AAMC.org)
77. Kagawa-Singer M, Kassim-Lakha S (2003) A strategy to reduce cross-cultural miscommunication and increase the likelihood of improving health outcomes. *Acad Med* 78:577–587
78. Surbone A, Kagawa-Singer M, Terret C, Baider L (2006) The illness trajectory of elderly cancer patients across cultures: SIOG position paper. *Ann Oncol* 18:633–638
79. Surbone A (2008) Cultural aspects of communication in cancer care. *Supp Care Cancer* 16:235–240
80. Airhihenbuwa C, Kumanyika S, Agurs TD, Lowe A (1995) Perceptions and beliefs about exercise, rest, and health among African-Americans. *Am J Health Promot* 9:426–429
81. Surbone A (2004) Persisting differences in truth-telling throughout the world. *Supp Care Cancer* 12:143–146
82. Mystadikou K, Parpa E, Tsilika E et al (2004) Cancer information disclosure in different cultural contexts. *Support Care Cancer* 12:147–154
83. Surbone A (2006) Telling truth to patients with cancer: what is the truth? *Lancet Oncol* 7:944–950
84. Kagawa-Singer M, Blackhall LJ (2001) Negotiating cross-cultural issues at the end of life: “You got to go where he lives”. *JAMA* 286:2993–3001
85. Betancourt JR, Green AR, Carrillo JE, Ananeh-Firempong O 2nd (2003) Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Rep* 118:293–302
86. Nguyen TU, Kagawa-Singer M (2008) Overcoming barriers to cancer care through health navigation programs. *Semin Oncol Nurs* 24:270–278
87. Hutchison SD, Steginga SK, Dunn J (2006) The Tiered model of psychosocial intervention in cancer: a community based approach. *Psycho-Oncology* 15:541–546
88. ONS Position Statement, Psychosocial Services for Patients With Cancer, Approved by the Board of Directors March, 2008 from <http://www.ons.org/Publications/positions/Psychosocial.shtml>
89. Cavalli F (2008) The World Cancer Declaration: a roadmap for change. *Lancet Oncol* 9:810–811
90. IPOS-ESO Core Curriculum in Psycho-Oncology. Available at [www.ipos-society.org](http://www.ipos-society.org) or [www.cancerworld.org](http://www.cancerworld.org)
91. National Breast Cancer Center and National Cancer Control Initiative, 2005. Clinical practice guidelines for the psychosocial care of adults with cancer. Available at <http://www.nhmrc.gov.au/publications/pdf/cp90.pdf>
92. Ellis J, Lin J, Walsh A et al (2009) Predictors of referral for specialized psychosocial oncology care in patients with metastatic cancer: the contribution of age, distress, and marital status. *J Clin Oncol* 27:699–705
93. Stanton AL, Ganz PA, Kwan L et al (2005) Outcomes from the Moving Beyond Cancer psychoeducational, randomized, controlled trial with breast cancer patients. *J Clin Oncol* 23:6009–6018
94. Mandelblatt JS, Cullen J, Lawrence WF et al (2008) Economic evaluation alongside a clinical trial of psycho-educational interventions to improve adjustments to survivorship among patients with breast cancer. *J Clin Oncol* 26:1684–1690
95. Kash KM, Mago R, Kunkel EJ (2005) Psychosocial oncology: supportive care for the cancer patient. *Seminars Oncol* 32:211–218