The Oncological Patient in the Palliative Situation

Steffen Eychmueller, Diana Zwahlen and Monica Fliedner

Abstract

Palliative care approaches the patient and his or her suffering with a biopsychosocial-spiritual model. Thus, it is the strength of palliative care to complement the diagnosis driven approach of medical cancer care by a problem and resources-based assessment, participatory care plan, and patient-directed interventions. Interventions need to reflect timely prognosis, target population (the patient, the family carer, the professional), and level of trust and remaining energy. In palliative care the relevance of psycho-oncological aspects in the care of the terminally ill is considerable in the understanding of the overall suffering of patients approaching death and their loved ones and in their care and support. There is little evidence to date in terms of clinical benefit of specific psycho-oncological interventions in the last months or weeks of life, but there is evidence on effects of stress reduction and reduced anxiety if locus of control can stay within the patient as long as possible. One major difficulty in psychosocial research at the end-of-life, however, is defining patient relevant outcomes.

S. Eychmueller (✉) · M. Fliedner
University Center for Palliative Care, Inselspital Bern, Bern, Switzerland
e-mail: steffen.eychmueller@insel.ch

D. Zwahlen
Department of Oncology, University Hospital Basel, Bern, Switzerland

U. Goerling (ed.), *Psycho-Oncology*, Recent Results in Cancer Research 197,
DOI: 10.1007/978-3-642-40187-9_5, © Springer-Verlag Berlin Heidelberg 2014

Contents

A Patient's Journey: Mrs. B

Mrs. B. is a 58 years formerly very active and athletic woman whose husband died some years ago from cardiac arrest. We, the palliative care inpatient consult team and the patient, met for the first time on a surgical ward where she was hospitalized for abdominal pain and vomiting both due to progressive cholangiocarcinoma. Unintendedly, she broke out into tears when telling about the recent months: after primary surgery she underwent chemotherapy, and despite experience of fatigue she felt pretty well, continued to play tennis, and meet with friends and family. She did not at all expect her cancer to grow during this treatment, and now she feels dramatically disappointed; not only that her cancer was growing again, but also that she misjudged her body's condition. The sudden change in body condition and the new perspective lead to an overall weakness and break down. The former nurse saw herself for the first time in a new role as a patient, dependent on the help of others and most of all as being a burden for her daughter.

We discussed her preferences ("going home, no additional chemotherapy"), her worries ("becoming a burden for her daughter and the whole issues of dying"), her network at home ("nice home, living on my own, daughter with small children living closed by, son abroad for work"), and potential support needs for the future ("most important, providing psychological support for my daughter"). It was proposed to discuss the issues such as role changes in the family and the fear of being a burden and not being able to support others anymore, respectively, together with the psycho-oncologist.

After referral to the palliative care ward we organized a family conference including "skype-link" to her son. Abdominal pain and vomiting improved through medication, complementary therapy, and nutritional counseling. It was the patient herself who finally lead the family conference based on a structured problem-based prompt sheet ("SENS"-structure, i.e., discussion regarding Symptom management, End-of-life decisions based on individual preferences, Network-organization issues for the future care at home, and Support needs of family carers).

Mrs. B. returned home, stayed for several weeks managing symptoms by herself, with little support by her general practitioner, managing her household with external support twice a week, and—most important—meeting regularly with her daughter and grandchildren. Several sessions with the psycho-oncologist lead to open and honest discussions between mother and daughter about family roles, needs, fears, and finally to a better acceptance of role changes and support. The daughter herself wished for further psychotherapeutic support and was referred to a psychotherapist in private practice.

Three days before Mrs. B. died she returned to our palliative care ward accompanied by her entire family, asking for professional help for these last days, recognizing that no energy was left to survive any longer. She was greatly satisfied to have the opportunity to spend valuable time together with her family, experiencing security through the "net" around her and "the final growth, the completion of her life's symphony" even if the end was far too early.

1 Introduction

"Palliative care" or "palliative situation" is still poorly defined and the concept remains vague. Ellen Fox wrote in 1997 a remarkable editorial in the JAMA highlighting the "predominance of the curative model of medical care," as a "residual problem" (Fox 1997). Mrs. B's last weeks could have been easily filled with several medical interventions, which would have resulted in spending most of her remaining lifetime in the hospital. She was in a "palliative situation" and chose the model of care provided by palliative care. Fox continued: "…on a basic level, the curative model conflicts with the notion of a good death." There is a certain danger to omit individual values and goals and the "tendency to perceive patients in terms of their component parts."

Thus, it is the strength of palliative care to complement the diagnosis driven approach of medical cancer care by a problem-based assessment, participatory care plan, and patient-directed interventions. Consequently, palliative care approaches the patient and his or her suffering with a biopsychosocial-spiritual model. It is the aim of palliative care to give back as much self-control as possible to the patient and to provide support wherever and whoever is needed. The target of such care is less a cell or an organ, but the patient and her or his carers—or by words of Dame Cicely Saunders—the unit of care. Collaboration within the palliative care team and among professionals with different backgrounds is a frequent term when discussing and planning patient care. In palliative care the relevance of psycho-oncological aspects is considerable in the understanding of the overall suffering of patients approaching death and their loved ones and in their care and support. Psycho-oncology and palliative care share the view of seeing the patient as a whole and the suffering not only as a medical problem. Both include in their definitions the psychosocial aspects of somatic illness. Both regard the nonmedical aspects as essential part of suffering. Psycho-oncology and palliative care are both frequently involved in the care of patients with advanced cancer, but there is little evidence about "dosage," best time for involvement and process of interaction of these two fields.

There is a substantial overlap of the two definitions of psycho-oncology and palliative care, a fact that explains potential conflicts but which also how they complement each other in daily clinical care. There may be side effects of palliative care and psycho-oncology that need to be recognized early if used alone or in combination. One is adding distress to the patient and family by an overdose of support and/or insufficient coordination of care. Another is to disregard the patient's own resources even in a clinical situation of weakness and frailty, and to focus—as we do in medicine in general—on deficits rather than strengths and resources. In addition, it is of highest importance to distinguish three levels of interaction and reflection: The patient, the patient's surrounding or family, and finally the professional team.

In 2003, Breitbart edited for the first time the journal "Palliative & Supportive Care," "the first international journal of palliative medicine that focuses on the psychiatric, psychosocial, spiritual, existential, ethical, philosophical, and humanities aspects of palliative care" (Breitbart 2003). In a personal reflection Breitbart (2006) challenges one of the most significant values in palliative care and in psycho-oncology: time. Time is of the essence—for reflection, creating trust, and a relationship, doing "unfinished business," coping, communicating, but also for setting priorities: how would I like to spend my remaining lifetime, with whom and where?

This chapter will discuss and highlight recent advances in palliative care with particular focus on psycho-oncological aspects. The authors attempt to focus on data derived from specific studies in a "palliative care" population (which is still difficult to define!): from assessment to interventions having in mind a common "credo": professionalism in palliative care and psycho-oncology relies on the capability to continuously evaluate if treatment and care allow and give back a certain sense of control to the patient and family, of coherence, as Antonovsky defined, even in a "palliative situation"—and provides space and time for essential issues at the end-of-life.

2 Assessment

2.1 When

Possibly THE major issue in palliative care is late referral. In psycho-oncology and palliative care access to this kind of support and care is still lacking clearly defined "red flags," thus the recognition of needs remains unsystematic.

Today, recognition or "diagnosis" of important psychosocial and spiritual distress and palliative care needs in patients with advanced cancer has been highlighted in several guidelines, e.g., (Network 2003). In clinical practice, however, staffing, scientific recognition, routine screening, and financial reimbursement still pose significant barriers for early integration of palliative care in standard oncology care.

There is growing evidence that early integration of palliative care—several months prior to death—not only reduces distress and improves quality of life, but also decreases health care utilization and lastly costs (Temel et al. 2010, 2011; Zhang et al. 2009). Evidence seems to be sufficient for the American Society for Clinical Oncology (ASCO) to recommend early palliative care as best practice in some cancer diagnoses (Smith et al. 2012).

Late referral to psycho-oncological services too is a major issue in cancer care. Psychological disorders like adjustment disorders, anxiety disorders, or depression, only represent a portion of the reasons why cancer patients and their family members should be offered psycho-oncological care. The more general term, distress, is more appropriate for describing the psychosocial difficulties—whether they fulfill the criteria for a psychiatric disorder or not—experienced by many patients and their family members. Estimates are high regarding the number of patients and family members who do not fulfill the formal criteria for a psychological disorder according to the ICD or DSM but they do suffer from clinically relevant psychosocial distress (Bultz and Carlson 2005; Herschbach and Heusser 2008; Holland 2006).

International guidelines also reflect the urgency to quickly and efficiently identify (according to a predefined cut-off) individuals who may require more intense diagnostic and potentially psycho-oncological care (Holland et al. 2007). The standards for care of patients exhibiting psychosocial distress described by the NCCN are of particular importance in this area (National Comprehensive Cancer Network 2003).

Early diagnosis and referral of patients for psychosocial support are especially important with respect to psycho-oncological care, because comorbid psychiatric and psychosocial symptoms not only complicate treatment, but also negatively impact the quality of life of patients and their family members, adversely affect compliance, and lead to poorer medical treatment results (Colleoni et al. 2000; Faller et al. 1999; Ganz 2008; Parker et al. 2003).

2.2 What

Assessing and documenting complexity are one of the big challenges in palliative and end-of-life care. This is also true for the organization of tasks and responsibilities in an inter-professional care team, but also for financial/reimbursement issues. Comprehensive cancer care is one of the attempts to organize such tasks and responsibilities through a shared care model. One of the challenges in highly complex situations as we encounter them in palliative care can be seen in the fact that medical diagnoses alone may not reflect sufficiently individual problems and suffering.

The MASCC Psychosocial Study Group recently published a conclusive paper on main psychosocial concerns and needs of cancer patients and families throughout all phases of the disease (Surbone et al. 2010). In this document we find a call for action in terms of systematic assessment, training and even 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,…"

Thus, multidimensional assessment of problems or stressors is regarded as highly relevant in palliative care. For the purpose of providing a problem-based assessment system in palliative care, with symptom assessment as only one part of it, the "SENS"-system has been developed (Eychmuller 2012). Adding the problem-based SENS system as a parallel system to medical diagnosis in clinical practice has provided guidance for planning, prevention, concrete care, and coordination of care not only for the patient but also for the family system around him/her. Expectations and hope can be redirected toward actual goals and daily activities instead of medical procedures with sometimes questionable or unclear outcomes.

Other multidimensional or rather multiple-symptom-assessment systems in palliative care are commonly used in clinical practice but all rely on the patient's cognitive function which can alter dramatically even within days or hours. Based on NCCN Clinical Practice Guidelines for Supportive Care, the Edmonton Symptom Assessment System (ESAS) or single item tools for various symptoms (Butt et al. 2008) can be used. As for other tools a score of 4 or more on such screening instruments signifies at least moderately severe symptoms. Most studies on multi-symptom assessment tools are developed and tested mainly in ambulatory patient populations except ESAS.

It is for this reason that assessment in palliative care must be tailored to the patient's situation. Burden and length of the assessment must be minimized and the type of assessment must be related to concrete implications. This means that assessment instruments should have a screening tool character and serve as a foundation to support or enable further communication not necessarily linked directly to the patient but to family and team about the components of despair and possible resources of support. Going back to our patient example, Mrs. B., her distress at the beginning of the contact with the palliative care professionals was the loss of control and her fear to burden her daughter. Her distress did not correspond to symptoms of depression or anxiety nor was it the pain only which made her suffer most. A sensitive and focused dialog only could reveal needs and potential sources of support.

2.2.1 Depression and Anxiety

In a meta-analysis of studies performed with patients in palliative cancer care, Mitchell et al. (2011) reported interesting data. Stratified for various classification systems (ICD, DSM) as well as for stage of disease, this review did not support previous higher percentages of depression in patients with cancer (depression or adjustment disorder 24.7 %, all types of mood disorder 29.0 %). In addition, the study did not reveal any significant difference between palliative care and non-palliative care settings.

Surprisingly, adjustment disorders or anxiety seemed to be slightly more common in non-palliative patients. This might be explained again by the heterogeneous definition of "palliative situation."

Prevalence of anxiety and its relationship to psychological distress in the "palliative patient" is poorly understood. A recent study in terminally ill cancer patients showed moderately increased symptoms of anxiety in 18.6 % and clinically relevant symptoms in 12.4 % of participants. The levels of anxiety did not differ in outpatients versus palliative care inpatients. The Hospital Anxiety and Depression Scale was used to measure symptoms of anxiety and depression, and was administered along with measures of hopelessness, desire for hastened death (Kolvaet al. 2011). Palliative care inpatients reported significantly more symptoms of depression and desire for hastened death. The authors believe that an imminent death may lead to an increase of these symptoms.

Anxiety, however, plays an important if not dominant role in symptom perception and expression especially in pain. It is well known from multiple studies in neuropsychology and -physiology that uncertainty and pain are directly linked (Brown et al. 2008; Yoshida et al. 2013). Clinicians therefore need to explore in depth patients' fears and beliefs together with standard symptom assessment.

2.2.2 Demoralization, Hopelessness, and Wish for Hastened Death

There are many components of despair at the end-of-life. While some patients suffer from depression and anxiety others do not fulfill the criteria for these psychiatric diagnoses but suffer from demoralization and hopelessness or loss of meaning—symptoms and syndromes that cannot be categorized according to psychiatric diagnosis. Kissane et al. (2001) wrote an informative article about the importance of demoralization in palliative care, Nissim et al. (2009) investigated the desire for hastened death and hopelessness and Chochinov et al. (2008) looked at dignity. To be aware of and to assess demoralization and hopelessness and the wish for hastened death might be crucial to support some patients in the palliative situation.

2.2.3 Assessing Quality of Life

WHO (2002) defines quality of life as the predominant outcome of palliative care. In clinical practice, however, evaluation of individual quality of life can be difficult. Patients are often too weak and cognitively unstable to provide reliable answers to quality of life assessment tools or questionnaires. In addition most tools have not been evaluated adequately in this challenging clinical situation (Albers et al. 2010). While acknowledging such limitations, highly individualized quality of life measurement tools such as McGill Quality of Life Questionnaire (Cohen and Mount 2000; Cohen et al. 1997) and more recently the SMiLE—instrument (Fegg et al. 2008) have been specifically developed and tested in patients with far advanced cancer or other diseases. The idea behind both instruments, as an example, is to assess individual domains that may contribute to patient-related quality of life and at the same time to give weight to these domains in regard of actual importance. Results from the studies are encouraging but such an approach seems to be linked to research protocols rather than to daily routine.

Intermezzo: Mrs. B

This patient may not be representative for all patients suffering from advanced cancer. Mrs. B. had a long story of self-effectiveness and a rather high level of need of keeping control of her life. Thus, it is no surprise that during assessing her needs and strengths, it was easy to define her goals and to collaborate actively to give weight and priority to various aspects. She was clear in defining worries in regard to her daughter as priority number 1. She was clear in choosing her preferred place of care (at home) and to assess quantity and quality of her individual care team apart from her daughter. She regained control over her miserable illness in the moment, when medical reasoning was complemented by problem-based assessment and care planning. We might underestimate the effect of activating individual coping mechanisms when switching from medical language and diagnosis to day-to-day problems and related problem solving skills.

3 Care Plan

3.1 Multi-professional Teamwork

With increased complexity of the patient and his or her family's situation and depending on the amount of emotional distress in the system, specialized palliative care, and psycho-oncological interventions are required. Thus, in more complex situations the coordination of interdisciplinary support is essential.

Psycho-oncology and palliative care are both frequently involved in patients with advanced cancer, but there is little evidence about "dosage," best time for involvement and process of interaction of these two domains. "The most successful psycho-oncology, psychosocial and behavioral oncology units have been those able to use this diversity to their advantage by evaluating patients and referring them to the most appropriate resource. They function as truly multidisciplinary organizations, drawing on the knowledge of each to enrich the others, while remaining fully integrated in the patients' total medical care"(Holland 2006). The "team" by itself in consequence may become a healing factor—or if distressed and badly coordinated—a risk factor for the patient and family (Nakazawa et al. 2010).

Intermezzo: Mrs. B

The crucial point in Mrs. B.'s patient journey was the moment of taking over the leadership for her remaining lifetime (Detering et al. 2010). Based on her previous life experiences this shift back to control was the key: it was up to her to organize continuity of care and "her" network at home. It was up to her to decide and anticipate that her place for dying might be NOT at home but on the palliative care ward whenever possible; it was up to her to make active plans for the limited amount of time; it was up to her to make peace with her limited physical function.

And it was finally up to her to discuss with her daughter the need for psychological support including the time of bereavement.

4 Interventions

As recommended by various guidelines (e.g., NCCN) best symptom control, advance care planning, and care of the dying should be an integral part of any intervention near the end-of-life. Training in self-administration of drugs (enteral or subcutaneously) by the patient or a family member plays an important role in any crisis intervention (Shipley and Fairweather 2001). Dealing with fatigue and loss of appetite has been reported repetitively to become an important topic in each oncological consultation—not only for the patient, but also for the family (NICE 2011). But palliative care interventions offer more than just "symptomatology," and there might be a danger to overmedicalize treatment.

Not only medical treatment can be overdosed but psycho-oncological support too must be sensitively tailored to the patient and his or her family's situation and the limitations of the circumstances depending on factors such as time, cognitive functioning, and level of energy. Due to limitations and depending on the risk of acute deterioration, interventions usually should be focused on immediate positive effects on despair and acute stressors. As the EAPC paper (European Association for Palliative Care) (Junger and Payne 2011) puts it *In fact, claims regarding the relevance and effectiveness of psychological support provided to dying patients and their relatives should be made with caution. When defining their own professional role, tasks and responsibilities, psychologists should reflect critically upon the real benefits of their contribution. They should avoid a 'pathologisation' or 'psychologisation' of the normal intrapersonal and interpersonal challenges in the context of physical and existential suffering near the end of life.*

A recent qualitative study gives insight to a better understanding of the factors influencing the readiness of patients to address emotional needs (Baker et al. 2012). Results pointed to the fact that many patients do not openly share their emotional difficulties for a variety of reasons. Almost all patients indicated emotional distress or vulnerability. However, for many it felt important not to address distress. The key reason for not wanting to talk about distress was that emotional and mortal vulnerability appeared to be closely linked and patients expected that talking about distress might increase their experience of vulnerability. The key to understand the attitudes of patients was to look at the stage in the treatment trajectory they were at. Recently diagnosed patients were generally negative about being prompted to address distress. Patients interviewed some time after their diagnosis and completed treatment, were generally positive. The study, however, did not include patients on the palliative care ward.

As mentioned above psychiatric diagnoses such as depression and anxiety might be one indication for psycho-oncological support and counseling. But psycho-oncological support in the palliative patient might also be helpful when the components of despair are differing from specific symptoms of psychiatric disorders—as in our patient example Mrs. B.

The EAPC suggests distinguishing between four levels of psycho-oncological interventions in the palliative situation. 1. Compassionate communications and general psychological support, 2. Psychological techniques such as problem solving, 3. Counseling and specific psychological interventions such as anxiety management, and 4. Specialist psychological interventions such as psychotherapy.

Basis of psycho-oncological support and essential for most terminally ill patients and their families is a sustainable and trustful relationship. The importance of the relationship cannot be underestimated in the palliative situation as most patients have a sense of loss of control and vulnerability. The circumstances often lead to a rapidly intensified relationship between patient and psycho-oncologist as well as the awareness of time limits and approaching death might lead to personal developments that can be supported by general psychological support. These aspects demonstrate how difficult it is to measure how and why patients and families might benefit from psycho-oncological support at the end-of-life. One major difficulty in psychosocial research at the end-of-life however is defining patient relevant outcomes.

Nonetheless there is evidence for specialist psycho-oncological interventions with particular tailoring to terminally ill patients as Breitbart et al. (2010, 2012) showed in a meaning centered group setting. One other promising approach is dignity therapy (Chochinov et al. 2011). These first results for a specific population demonstrate both, feasibility, and clinical benefit, and can be considered as promising strategies for the future.

4.1 Outcomes and Expectations

However, one of the major sources for distress—for patients, but also partners/family and professional carers—can be found in overoptimistic or unrealistic expectations in any intervention in our world of "doing" and feasibility. Calman (1984) introduced a concept in regard to discuss and tailor patient (and carer) expectations as a central strategy to avoid additional distress. These early results have been studied repetitively, among others by Mack et al. in palliative and psycho-oncological care. The Calman gap concept remains one of the pragmatic approaches for physician/psychologist-patient interaction and highlights the importance of the concept of expectations (Broderick et al. 2011). Physical activity frequently cannot be altered or improved which may be difficult to accept especially for sportive people as in our case report. Therefore, physical activity should be replaced or complemented by psychological, social and/or spiritual activity—a strategy that sometimes may patients feel helpless and lost in to date unknown world. Thus, for any intervention we offer to a severely ill person with low level of energy and short timely prognosis, we should consider potential harm in terms of unrealistic expectations and/or lack of individual coping strategies.

5 Summary

Mrs. B. was not able to tell her family and the professional team about her experiences in the very last days of her life. But she could tell the family and the professional carers how important these last weeks at home surrounded by her family were to her. The family on the other hand told the professional team that the joint care planning, its discussion, and finally all interventions responded not only to her mother's needs and wishes, but also integrated at its best the family—and helped to reduce family distress at least to a manageable amount.

Providing space and security for essential things to happen, and to give back a sense of control even in a situation of weakness and fatigue—such elements seem to be mandatory for the final months of life. In times of cost-effectiveness and evidence-based objective measurements this therapeutic approach may be primarily considered as non-scientific, but evidence from neuropsychology, physiology, and from (randomized) controlled trials in assessment and interventions in psychosocial and even spiritual care increasingly support such strategies. The stress-model and recent advances in brain research may add additional evidence and build the bridge to a more scientific acceptance of a humanistic approach. The whole story seems to be about stress reduction and even "healing" in an otherwise desperate life situation, with "healing" being applied not only to the patient, but also to family carers and professionals (Mount and Kearney 2003). Research may finally turn out to support historic findings as formulated earlier by Paracelsus (1493–1541): "Die beste Arznei für den Menschen ist der Mensch. Der höchste Grad dieser Arznei ist die Liebe. Or: the best drug for humans is a human. The highest degree of this drug is love."

References

Albers G, Echteld MA, de Vet HC, Onwuteaka-Philipsen BD, van der Linden MH, Deliens L (2010) Evaluation of quality-of-life measures for use in palliative care: a systematic review. (Eval Stud Rev) Palliat Med 24(1):17–37. doi: 10.1177/0269216309346593

Baker P, Beesley H, Dinwoodie R, Fletcher I, Ablett J, Holcombe C, Salmon P (2012) You're putting thoughts into my head: a qualitative study of the readiness of patients with breast, lung or prostate cancer to address emotional needs through the first 18 months after diagnosis. Psychooncology. doi:10.1002/pon.3156

Breitbart W (2003) Palliative and supportive care: introducing a new international journal; the "Care" journal of palliative medicine. Palliat Support Care 1(1):1–2

Breitbart W (2006) Waiting. Palliat Support Care 4(3):313–314

Breitbart W, Poppito S, Rosenfeld B, Vickers AJ, Li Y, Abbey J, Cassileth BR (2012) Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer (Comparative study randomized controlled trial research support, non-US gov't). J Clin Oncol, 30(12):1304–1309. doi: 10.1200/JCO.2011.36.2517

Breitbart W, Rosenfeld B, Gibson C, Pessin H, Poppito S, Nelson C, Olden M (2010) Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial (Randomized controlled trial research support, NIH, extramural research support, non-US gov't). Psychooncology 19(1):21–28. doi: 10.1002/pon.1556

Broderick JE, Junghaenel DU, Schneider S, Bruckenthal P, Keefe FJ (2011) Treatment expectation for pain coping skills training: relationship to osteoarthritis patients' baseline psychosocial characteristics (Clinical trial multicenter study randomized controlled trial research support, NIH, research support, non-US gov't). Clin J Pain 27(4):315–322. doi: 10.1097/AJP.0b013e3182048549

Brown CA, Seymour B, Boyle Y, El-Deredy W, Jones AK (2008) Modulation of pain ratings by expectation and uncertainty: behavioral characteristics and anticipatory neural correlates (Research support, non-US gov't). Pain 135(3):240–250. doi: 10.1016/j.pain.2007.05.022

Bultz BD, Carlson LE (2005) Emotional distress: the sixth vital sign in cancer care (Comp Stud Lett). J Clin Oncol 23(26):6440–6441. doi: 10.1200/JCO.2005.02.3259

Butt Z, Wagner LI, Beaumont JL, Paice JA, Peterman AH, Shevrin D, Cella D (2008) Use of a single-item screening tool to detect clinically significant fatigue, pain, distress, and anorexia in ambulatory cancer practice. J Pain Symptom Manage 35(1):20–30. doi: 10.1016/j.jpainsymman.2007.02.040

Calman KC (1984) Quality of life in cancer patients: an hypothesis. J Med Ethics 10(3):124–127

Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, Murray A (2008) The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care (Research support, non-US gov't). J Pain Symptom Manage 36(6):559–571. doi: 10.1016/j.jpainsymman.2007.12.018

Chochinov HM, Kristjanson LJ, Breitbart W, McClement S, Hack TF, Hassard T, Harlos, M (2011) Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial (Comparative study randomized controlled trial research support, NIH, extramural research support, non-US gov't). Lancet Oncol 12(8):753–762. doi: 10.1016/S1470-2045(11)70153-X

Cohen SR, Mount BM (2000) Living with cancer: "good" days and "bad" days: what produces them? Can the McGill quality of life questionnaire distinguish between them? (Research support, non-US gov't). Cancer 89(8):1854–1865

Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K (1997) Validity of the McGill quality of life questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain (Research support, non-US gov't). Palliat Med 11(1):3–20

Colleoni M, Mandala M, Peruzzotti G, Robertson C, Bredart A, Goldhirsch A (2000) Depression and degree of acceptance of adjuvant cytotoxic drugs (Letter). Lancet 356(9238):1326–1327. doi:10.1016/S0140-6736(00)02821-X

Detering KM, Hancock AD, Reade MC, Silvester W (2010) The impact of advance care planning on end of life care in elderly patients: randomised controlled trial (Randomized controlled trial research support, non-US gov't). BMJ 340:c1345. doi: 10.1136/bmj.c1345

Eychmuller S (2012) SENS is making sense: on the way to an innovative approach to structure palliative care problems. Ther Umsch 69(2):87–90. doi:10.1024/0040-5930/a000256

Faller H, Bulzebruck H, Drings P, Lang H (1999) Coping, distress, and survival among patients with lung cancer (Research support, non-US gov't). Arch Gen Psychiatry 56(8):756–762

Fegg MJ, Kramer M, L'Hoste S, Borasio GD (2008) The schedule for meaning in life evaluation (SMiLE): validation of a new instrument for meaning-in-life research (Research support, non-US gov't validation studies). J Pain Symptom Manage 35(4):356–364. doi: 10.1016/j.jpainsymman.2007.05.007

Fox E (1997) Predominance of the curative model of medical care: a residual problem (Comment editorial). JAMA 278(9):761–763

Ganz PA (2008) Psychological and social aspects of breast cancer (Review). Oncology (Williston Park) 22(6):642–646, 650; discussion 650, 653

Herschbach P, Heusser P (2008) Einführung in die psychoonkologische Behandlungspraxis, 1st edn. Klett-Cotta, Stuttgart

Holland JC (2006) Psycho-oncology: from empirical research to screening program. In: Herschbach P, Heussner P, Sellschopp A (eds) *Psycho-onkologie, perspektiven heute* (pp 9–43): Pabst Science publishers

Holland JC, Andersen B, Breitbart WS, Dabrowski M, Dudley MM, Fleishman S, Zevon MA (2007) Distress management (Practice guideline). J Natl Compr Cancer Netw 5(1): 66–98

Junger S, Payne S (2011) Guidance on postgraduate education for psychologists involved in palliative care. Europ J Pall Care 18(5):238–252

Kissane DW, Clarke DM, Street AF (2001) Demoralization syndrome: a relevant psychiatric diagnosis for palliative care (Research support, non-US gov't review). J Palliat Care 17(1): 12–21

Kolva E, Rosenfeld B, Pessin H, Breitbart W, Brescia R (2011) Anxiety in terminally ill cancer patients (Research support, NIH, extramural). J Pain Symptom Manage 42(5):691–701. doi: 10.1016/j.jpainsymman.2011.01.013

Mitchell AJ, Chan M, Bhatti H, Halton M, Grassi L, Johansen C, Meader N (2011) Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies (Meta-analysis). Lancet Oncol 12(2):160–174. doi:10.1016/S1470-2045(11)70002-X

Mount B, Kearney M (2003) Healing and palliative care: charting our way forward (Editorial). Palliat Med 17(8):657–658

Nakazawa Y, Miyashita M, Morita T, Umeda M, Oyagi Y, Ogasawara T (2010) The palliative care self-reported practices scale and the palliative care difficulties scale: reliability and validity of two scales evaluating self-reported practices and difficulties experienced in palliative care by health professionals (Validation studies). J Palliat Med 13(4):427–437. doi: 10.1089/jpm.2009.0289

National Comprehensive Cancer Network (2003) Distress management clinical practice guidelines. J Natl Comp Cancer Network 1:344–374

Network NNCC (2003) Distress management: clinical practice guidelines (Practice guideline). J Natl Compr Cancer Netw 1(3):344–374

NICE (2011) The diagnosis and treatment of lung cancer (Update), vol 212. Cardiff (UK)

Nissim R, Gagliese L, Rodin G (2009) The desire for hastened death in individuals with advanced cancer: a longitudinal qualitative study (Research support, non-US gov't). Soc Sci Med 69(2):165–171. doi:10.1016/j.socscimed.2009.04.021

Parker PA, Baile WF, de Moor C, Cohen L (2003) Psychosocial and demographic predictors of quality of life in a large sample of cancer patients (Comparative study). Psychooncology 12(2):183–193. doi:10.1002/pon.635

Shipley V, Fairweather J (2001) A programme of individualized and self-administration of medicines in a hospice. Int J Palliat Nurs 7(12):581–586

Smith TJ, Temin S, Alesi ER, Abernethy AP, Balboni TA, Basch EM, Von Roenn JH (2012) American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. J Clin Oncol 30(8):880–887. doi: 10.1200/JCO.2011.38.5161

Surbone A, Baider L, Weitzman TS, Brames MJ, Rittenberg CN, Johnson J (2010) Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement (Practice guideline). Support Care Cancer 18(2):255–263. doi:10.1007/s00520-009-0693-4

Temel JS, Greer JA, Admane S, Gallagher ER, Jackson VA, Lynch TJ, Pirl WF (2011) Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: results of a randomized study of early palliative care (Randomized controlled trial research support, non-US gov't). J Clin Oncol 29(17):2319–2326. doi: 10.1200/JCO.2010.32.4459

Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Lynch TJ (2010) Early palliative care for patients with metastatic non-small-cell lung cancer (Randomized controlled trial research support, non-US gov't). N Engl J Med 363(8):733–742. doi: 10.1056/NEJMoa1000678

WHO (2002) Definition palliative care, 2013

Yoshida W, Seymour B, Koltzenburg M, Dolan RJ (2013) Uncertainty increases pain: evidence for a novel mechanism of pain modulation involving the periaqueductal gray. J Neurosci 33(13):5638–5646. doi:10.1523/JNEUROSCI.4984-12.2013

Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Prigerson HG (2009) Health care costs in the last week of life: associations with end-of-life conversations (Research support, NIH, extramural research support, non-US gov't). Arch Intern Med 169(5):480-488. doi: 10.1001/archinternmed.2008.587