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Review article

Palliative care and oncological patients

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A R T I C L E I N F O

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A B S T R A C T

Palliative care is an active and holistic concern for both the person whose illness no longer responds to treatment and the patient's family. Palliative care seeks to alleviate pain and suffering and improve the quality of life of the patient and his or her family. Palliative care not only alleviates physical symptoms but also helps with mental, social and spiritual difficulties. Palliative care supports family members during illness and in mourning after the patient's death. Palliative care celebrates life: it does not accelerate or delay death, considering it as part of a normal life process.

1. Introduction

The definition of culture, as an integrated pattern of learned beliefs and behaviors that include thoughts, styles of communicating, ways of interacting, values, practices, and customs has evolved, over time, but the underlying understanding is that culture is the lens through which people give the world meaning and which shapes their beliefs and behaviors (Florea, 2012). Culture is a system of shared ideas, concepts, rules and meanings that underlies the way we live and approach death. Cultural diversity refers to more than ethnic diversity; age, gender, sexual preference, capabilities, education, place of residence, and occupation also contribute to diversity of culture. Cultures change or evolve over time and this affects many areas. In palliative medicine attitudes and practices regarding care of the incurable patient, of the dying (and dead) have changed, from unspeakable neglect common to the multiple contemporary patterns. The role of culture is significant in palliative care, and how it is conceptualized and applied has enormous consequences for patients, families and health care providers. It influences communication patterns, decision-making styles, responses to symptoms, treatment choices, and emotional expression at end of life.

Palliative care clinicians face two troublesome issues in introducing themselves to a patient, family, or health care professional (Billings, 2002). First, the term “palliative care service” is still unfamiliar to many people. A simple, straightforward, concise explanation is called for, yet just a few words rarely suffice. Other specialists for example, a cardiologist (“a heart doctor”) or an orthopedist (“a bone surgeon”) are unlikely to be asked to define their field of expertise, nor feel challenged by the task. Second, a full explanation of palliative care necessarily refers to death, a potentially frightening topic that the patient and family, as well as the palliative care clinician, may wish to avoid, at least in the first moments of an interview. The clinician, before touching on such difficult matters as end-of-life care, wants first to listen to the patient and family and understand their perspectives and information preferences, as well as to avoid saying something “wrong.” A nuanced description of palliative care services, especially for strangers facing dying, is a challenge. Phrases such as “terminal care,” “life-threatening illness,” or even “seriously ill” may stick in the clinician's mouth. One searches for euphemisms in these opening moments, yet struggles to establish a relationship that is based on authenticity and measured frankness.

To complicate this awkward situation, interpretations of the meaning of palliative care and of its scope vary within the palliative care community, reflecting the evolving nature of this not-yet-fully-formed young field. The scope of palliative medicine remains an issue for debate, ranging from absurdly broad definitions as “alleviation of symptoms,” “improving quality of life,” or treating patients “not responsive to curative treatment” to extremely narrow notions of care in the last 6 months or less of life. Discussions of definitions and standards also raise a few, significant, unsettled political conflicts about the field's future. Approaches to identifying a final phase of life during which palliative care is appropriate have not been clinically useful. We lack elementary standards for palliative care programs staffing, professional training of staff, eligibility of patients and families for services, scope of services, and so forth. This unfortunate state may be viewed generously as an early stage in the development of a field that still is formulating its most basic features.

2. Cancer

It is at the extremes of life that cancer strikes (Rai and Webster, 2000). In childhood, it occurs mainly in the form of blood disorders, such as acute leukaemia and cerebral tumours. Both of these conditions can occur in later life, but cancers of other organs and systems also become much more likely. After middle age, the incidence of cancer rises, but different forms peak at different ages. For example, lung cancer peaks relatively early, at about 65 years, but most others peak at about 80 years of age. There is some evidence of a tailing off in the very extremes of old age; this is supported by both clinical and post-mortem evidence. Patterns of cancers differ between the sexes, sometimes for obvious reasons; for example, prostatic cancer occurs only in men and gynaecological cancer occurs only in women. The other malignancy which shows a marked sex difference is breast cancer, which can affect both sexes, but is predominant in women, whereas most other malignancies tend to be more common in men.

An elderly person with cancer is also likely to have co-existent pathologies (co-morbidity). This concurrent progression of illnesses will complicate the presentation and management of the cancer. Cancer is the second most frequent form of death in those aged over 65. It is exceeded by heart disease and just outnumbers deaths from strokes. Most people who die of cancer are old.

Frequently, inappropriate assumptions are made with regard to cancer in old age, for example, it is less aggressive, less important and more readily accepted by the patient. However, cancers differ, patients differ and so do their doctors. It is essential that, in all cases, irrespective of age, a full assessment of the patient and their problems is made, all options are considered and a reasoned conclusion and management plan are decided upon; the patient, as always, having the casting vote.

Most patients with cancer have a suspicion about their diagnosis from the time of their initial consultation. Most will want their fears confirmed once the diagnosis has been established. Some will prefer not to know and will deny any worries or concerns their wishes should be respected. However, it will make the initiation of appropriate treatment difficult, if not impossible, especially where detailed patient co-operation is needed.

Some children of patients, that is, middle aged adults, will try to be overprotective. They will fear that their mother or father will be unable to cope with ‘bad news’. Generally, these fears are unfounded and the elderly person will usually have already survived more psychological traumas than their children. Such anxious ‘children’ should be reassured and informed that competent adults (such as their parents) cannot be denied information relevant to their own well-being and future management, unless they themselves express a desire to remain in ignorance.

Breaking bad news is always difficult and distressing, and it should be done in as sympathetic and empathie a way as is possible, in suitable surroundings and circumstances. However, any patient who asks an honest question has the right to receive an honest answer, however inconvenient the timing or circumstances prevailing at that time. To prevaricate may be unkind. It is not always possible or appropriate to give the whole truth in a single sitting; it may be better to reveal the information in instalments.

3. Patients

Every patient has individual feelings and needs (Tannenberger, 2006). Sometimes, these are far from our expectations, organizational models and therapeutic approaches. Between patients living in developed and developing countries, there are differences with regard to not only the resources available for patients dying from cancer but also their experience of illness.

Palliative care for advanced cancer patients has to be focused strictly on the control of symptoms and the psychological support of patients and their families. Patients should be protected from non-evidence-based overtreatment, which often reduces their quality of life. However, the decision to cure or to care can be difficult. Moreover, many patients want to continue to fight and to feel they are being ‘treated’. The daily practice of palliative care should be tailored to the patient’s needs, which we have to understand by careful exploration. Healthcare professionals should encourage opportunities for carers to discuss their views of the ongoing needs of patients with advanced cancer.

Many palliative care patients prefer home care, and a majority of terminal patients want to die at home. For this reason, home care needs the greatest attention. However, the demographic situation makes it increasingly difficult to find family members who are willing to be caregivers at home. Therefore, parallel hospice organizations and palliative care units also deserve strong support. Only a well-organized network of specialized oncology, home-care and hospices/palliative care units can guarantee the fundamental human right of advanced cancer patients to live and die with dignity. Medical oncology should be the driver in establishing this network for palliative oncology.

4. Diagnosis

After a cancer diagnosis is established, the important question is whether the tumor is localized or metastatic (Yavuzsen and Komurcu, 2008). Metastasis and tumor invasion are the major causes of cancer treatment failure. Despite better diagnosis, surgical techniques, patient care, and adjuvant treatments, most deaths from cancer are from metastatic disease. Thirty percent of patients with newly diagnosed tumors have detectable metastases. Of the remaining 70% who are clinically free of metastasis, about one half have metastatic spread detected during follow-up. Metastases can be located in different organs or different regions of the same organ.

The metastatic process is not random and depends on multiple interactions between the organ’s microenvironment and the tumor cells. These factors include monoclonal expansion of tumor cells by genetic alterations and environmental factors such as viral infections inducing polyclonal expansion of the cells’ influences on normal tissues. After accumulation of genetic alterations in a few premalignant cells, the cells convert into malignant ones. By clonal expansion, the fully malignant cells become invasive and metastatic.

Common sites of metastatic disease are lung, bone, liver, brain, and other soft tissues. The site frequency depends on the primary tumor 4. It is sometimes possible to predict the most likely primary sites from the histologic and deposition pattern of metastases.

Palliation services have primarily covered cancer and cancer-related diagnoses because cancer was supposedly considered to be a terminal illness with the only difference being the speed of progression of various cancers (Gupta, 2012). Slowly with time, other medical diagnoses with similar clinical profiles of variable progression but eventual terminal endpoint found their desirable places in palliative medical care. Paradoxically, the improved survivorship of the cancer patients perpetrated the need of delayed palliation for these cancer patients. So the big question is which all medical diagnoses need palliation as part of their ongoing medical care when death is ultimate truth of all life and irrespective of any medical diagnosis, all patient populations may require palliative services at different time points in their medical lives.

The palliation as a concept can be instilled in the medical care as soon as it is recognized that the disease state will be running a chronic course that will require psychological, social and spiritual care besides the attempts at curative physical care. The dilemma is that based on the present understanding of the society about the palliative care, the early introduction of palliation model will confuse the patients, their families and the medical caregivers about the appropriateness of palliation. However, the answer does not lie in deterring the palliation till the very-end-of-life. Instead pioneering an education and awareness initiative for both patient population as well as medical community to realize the role of palliation in almost all disease stages will establish achievable prudent holistic care.

5. Palliative care

Modern palliative care promotes aggressive symptom management at all stages of treatment for a serious illness, from early disease treatment through end-of-life care (VandeKieft, 2012). According to the American Academy of Hospice and Palliative Medicine, “The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms, and restoration of functional capacity while remaining sensitive to personal, cultural, and religious values, beliefs, and practices”. This concept has been echoed by the Institute of Medicine, which also notes that “Palliative care in this broad sense is not restricted to those who are dying. It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them”.

Viewed from this context, it is clear that palliative care is a cornerstone not just of end-of-life care but also of chronic disease management. After all, diseases such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), arthritis, and Alzheimer disease are largely incurable, but much can be done to help the patient, and the goal of treatment is not only to extend life (a curative care principle) but also to maximize comfort, function, and quality of life. The difference at the end of life (i.e., in very advanced, terminal disease states) is that palliative care principles become paramount, and prolongation of length of life becomes much less important than quality of life.

6. Quality of life

Patients regularly ask physicians and nurses for quality of life information about their cancer and its treatment: “How much pain will I have? How much nausea and vomiting will the chemotherapy cause? How long will it last? Will I have enough energy to work? Is it safe for me to have sex? Will all my hair fall out? Will it come back? How much time will I have to spend in the hospital? How much is this all going to cost? When is my appetite going to come back? Why am I feeling so depressed? Will I ever stop being so nervous?” And they often ask the ultimate question that requires the physician to integrate knowledge of the anticancer treatment, the supportive care efforts, and the quality of life effect of the disease and the treatment: “Will I be better off because of this treatment?” Too often the answers given are limited to anecdotal, incomplete, or misinformed replies, because quality of life evaluations in cancer clinical trials and in palliative care have been uncommon, limited in scope, or difficult for the clinician to interpret (Skeel, 2002).

The goal of supportive care in oncology as is the goal of palliative care in any medical specialty is to make patients function and feel better than they would have without that supportive care. This goal is explicitly different from that of curative or life-extending therapy, in which there is regularly a moderate to high tolerance for side effects and temporary functional impairments. Even with curative or life-extending therapies, supportive care measures are necessary, and the success of the palliative aspects of care may determine whether the patient is willing to tolerate repeated courses of the treatment, as is usually necessary with chemotherapy. Whether the care is given in conjunction with other cancer treatments or is used exclusively to palliate the effects of the cancer, the criteria for success are that the patient feels and functions better. When patients are less pleased with how they are feeling or functioning that is, when they believe their quality of life is not better then the supportive care has not been successful. The patients' personal, subjective perception of how they are feeling and how they are functioning thus becomes a critical outcome measure of this aspect of cancer care.

The physical symptoms of disease and side effects of treatment that are common include fatigue, pain, nausea and vomiting, hair loss, and anorexia. Other symptoms of disease and treatment are quite specific to a disease or treatment and include problems such as incontinence of stool or urine, dyspnea from congestive heart failure or pulmonary toxicity, and peripheral neuropathies. Although these are discrete elements that contribute to global HQL, they also have an impact on functional capacity. The latter is usually separated into three distinct domains: psychological functioning, social functioning, and physical functioning. Psychological functioning includes anxiety, depression, adjustment to the disease and its treatment, and satisfaction with care. Physical functioning includes mobility, ability for self-care, and ability to carry on daily routine (e.g., child care or work activities). Social functioning includes family interactions, relationships with friends, and ability to function on the job beyond the physical level. Additional considerations in HQL may relate to spiritual concerns, sexual functioning, and body image. Variability among respondents may also occur because of the assessment environment, and the manner and form of evaluation. Thus, subjectivity and multidimensionality are two critical factors in understanding and measuring HQL and in interpreting data from HQL assessments.

7. Pain

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage (Noble, 2008). It is experienced by up to 70% of patients with advanced cancer and of these, one-third have a single pain, one third have two pains and one-third have three or more pains. Pain may be:

- ✓ Related to the cancer itself (e.g. metastatic bone pain).
- ✓ Treatment related (e.g. neuropathy secondary to chemotherapy).
- ✓ Related to cancer and debility (e.g. constipation).
- ✓ Unrelated to the cancer (due to another co-existing condition).

Advances in the diagnosis and treatment of cancer, coupled with an expanded understanding of the physiology, pharmacology, and psychology of pain perception, have led to improved care of the patient with pain from cancer (Foley, 2010). Improved methods of cancer diagnosis and treatment provide the best approach to managing pain by treating its cause. Before the start of antitumor therapy, or when such therapy is unsuccessful or irreversible injury to bone, soft tissue, or nerve has occurred, however, adequate pain control is essential.

Management of pain in patients with cancer requires specific expertise that includes a knowledge of the clinical pain syndromes that are common in cancer and their pathophysiologic mechanisms, the psychological state of the patient, and the indications and limitations of the available therapeutic approaches. Clinical experience suggests that patients with cancer pain are treated most effectively with a multidisciplinary approach that includes adequate analgesic drug therapy, neurological and anesthetic procedures, behavioral methods, and supportive care.

The goal of pain therapy for patients receiving active treatment is to provide them with sufficient relief to tolerate the diagnostic and therapeutic approaches required to treat the cancer. For patients with advanced disease, pain control should be sufficient to allow the patients to function at a level that they choose and to die relatively free of pain. Critical to the management of cancer pain is the establishment of a trusting relationship between the patient and a physician who takes the pain seriously and assesses its nature and severity.

Severe pain, which can undermine quality of life and cause incapacitating distress to patients and their accompanying family members, is a common consequence of advanced cancer and of other advanced incurable illnesses (Cherny, 2014). Patients have a right to the adequate relief of their pain, and indeed a strong case has been made for having this recognized as a basic human right. This right is derived from principles of respect for persons, beneficence, non-maleficence, and justice. Substantial obligations and duties derive from this claim that are relevant to individual health care providers (such as the professional staff attending to patients), the institutions in which they work, and the authorities responsible for public health policy in the provision and allocation of healthcare resources.

8. Nursing

Assessment of the patient and family is viewed as of central importance to the multidisciplinary management of the patient with palliative care needs (Fitzsimmons and Admedzai, 2004). To undertake an assessment, the palliative care nurse needs to be equipped with an in-depth knowledge base of the impact of advanced illness on the patient and family, and have skills in recognizing potential and actual health needs of patients and their families. Once a thorough assessment is undertaken, the nurse, in collaboration with the multidisciplinary team, can plan and implement appropriate care. The goals or outcomes of this care provision can then be evaluated. This is often done by evaluating the impact of care on patient-based outcomes such as symptom relief and quality of life.

Assessment is the first stage of the 'nursing process', which was devised to provide a more systematic approach to the provision of nursing care. It is important to recognize, however, that assessment is not a discrete step in the provision of nursing care but a dynamic process. In palliative care, patients' health needs can change rapidly, requiring the nurse to be sensitive, flexible and creative, based on assessment of an individual's ongoing needs. Furthermore, nursing assessment should go beyond assessment of symptoms, functional status and other physical problems associated with terminal illness. Recognition of the complexity and differences in each individual's experience of palliative care is dependent on an assessment process that allows the wider context of patients' social, emotional, cultural and spiritual needs to be explored fully.

9. Treatment

When dealing with cancer, the treatment is multifaceted, with one treatment mode or perhaps combinations being used depending on the patient's cancer, stage of disease, age, co-morbidity, general frailty, etc. (Aitken, 2009). Patients may just want to get started with their treatment, believing that any delay may jeopardise their survival; however, they do need time to adjust to their diagnosis, obtain all the relevant information, make decisions regarding treatment and fully discuss issues with their oncologist. Treatment should be started as soon as possible, but delays of a few weeks probably make little difference to the final outcome of the cancer; however, this needs to be conveyed to the anxious patient. The main treatments for cancer comprise surgery, chemotherapy or radiotherapy, although other treatments such as immunotherapy or hormone treatment, for example, may be used. Mixed in with this cocktail of treatments is also the need for symptom control and management of the patient's emotional distress.

After discussion with the patient, a referral may be passed onto the community palliative care clinical nurse specialist from the oncologist or general practitioner to assist the patient in understanding the proposed treatment and to offer emotional support during this distressing time. The role of the community palliative care clinical nurse specialist is to assist patients to understand what has been discussed with their doctors, in regard to the treatment on offer, its potential benefits in relation to their disease, length of treatment and side-effects. Explanation can be given to patients in their own home, where they may be able to ask more questions and absorb more of the details of what is being communicated. This follow-up interview also enables questions to be answered that may have arisen in the interval between the patient seeing the hospital consultant and the nurse visiting.

10. Rehabilitation

Palliative rehabilitation encompasses supportive approaches designed to reduce patients' dependence in mobility and self-care activities (Cheville et al., 2007). Emotional support and comfort are concurrently provided. For example, preservation of autonomous bowel and bladder continence is an important palliative goal in cancer patients with advanced disease. The presence of incontinence predicts profound psychological distress. Simple rehabilitative interventions can often extend patients ability to toilet independently till the very terminal stages of cancer. Anasarca (generalized edema) and progressive lymphedema are common among end-stage cancer patients. Palliative rehabilitation approaches such as lymphatic drainage techniques and multi-layer compression bandaging can minimize edema, thereby enhancing patient comfort and mobility. Additionally, these measures function preventatively to reduce the likelihood of local skin breakdown and infections.

11. Conclusion

Palliative care is comprehensive care for people with incurable illness who no longer respond to treatment. By making the diagnosis, and subsequently by suspending active treatment, the patient and family experience emotional shock, often without hearing what they are told, and feeling rejected. Palliative care from the outset can help overcome such situations and provide adequate psychological help. Palliative care is an active care, health, psychological, social and spiritual, for the patient and for the patient's family. Care is focused on alleviating and resolving unpleasant physical symptoms of the disease, the most common of which are pain, nausea, vomiting, constipation, and dehydration. In addition, the goal of palliative care is also to provide psychological assistance and support to the patient and the family throughout care. This improves the quality of life and enables a dignified life to the end.

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