

Palliative and supportive care: At the frontier of medical omnipotence*

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Summary

Cancer patients have physical, social, spiritual and emotional needs. They may suffer from severe physical symptoms, from social isolation and a sense of spiritual abandonment, and emotions such as sadness and anxiety, or feelings of deception, helplessness, anger and guilt. In some of them, the disease is rapidly progressive and they ultimately die. Their demanding care evokes intense feelings in health care providers, the more so since these incurable patients represent a challenge, which can be characterized as one of 'medical

omnipotence'. It may be assumed that the way health care providers cope with these circumstances profoundly influences the way these patients are cared for. Attitudes regarding the emerging heterogeneous movement of palliative and supportive care and its different models of implementation can be viewed from this vantage point. Here we look at these interrelations and discuss the potential pitfalls if they are ignored and remain unexamined.

Key words: cancer, palliative care, psycho-oncology, supportive care

The following thoughts about palliative and supportive care derive from clinical experiences in oncology, psycho-oncology, psychiatry and palliative care. This view is certainly a subjective one, influenced by the authors' specialization as psychiatrists. It does not purport to be a comprehensive, in-depth investigation of the topic, but is submitted for reflection and discussion.

Cancer patients may suffer from physical symptoms, feelings of spiritual abandonment and social isolation, and intense emotions. Health care providers treating these patients face a difficult biopsychosocial situation, and at the same time must cope with their own feelings evoked by these circumstances. And they also have to deal with the challenge which incurable cancer patients present to their medical identity, usually defined by the success they achieve in fighting for life. From our experience, we argue that these circumstances have a profound impact on the way the care of cancer patients is conceptualized.

A short overview of the development of palliative and supportive care

While treatments with curative intent dominated the early history of oncology [1–3], a movement promoting the importance of non-curative, so-called palliative or supportive treatments, has evolved from the pioneer work of Dr. Cicely Saunders, who founded St. Christopher's Hospice in London in 1967 [4]. Palliative care

is defined by the World Health Organization as an active total care of patients whose disease is not responsive to curative treatment [5]. Supportive care, a more recent term indicating a different conceptualization, is concerned with the optimal well-being of cancer patients in all stages of their often long and complicated disease. Supportive care covers all aspects of support in oncology, during curative treatment phases and in advanced and terminal stages of disease. Its non-tumor-directed therapeutic strategies include supportive interventions such as pain control, psychosocial and spiritual aid, antiemesis, adequate control of infections or nutritional support. Palliative care addresses the patients without hope of cure and is therefore only one aspect of the broad umbrella of supportive care [6]. While in some countries physicians and nurses working in oncology and geriatrics were among the first to support this movement, in other places such as Britain, palliative care was mainly developed separately from hospital-based medicine. Palliative and supportive care is now conceptualized and implemented in different forms and is no longer restricted to cancer patients. Depending on local circumstances, palliative and supportive care services are established as home care services [7], hospital-based consultation services [8], as hospital-based inpatient units [9] or as independent hospices [10]. Some of these services are also accessible to patients with AIDS, end-stage renal disease and other medical conditions [11]. The variety of terms used to characterize this evolving discipline makes it

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difficult to compare the actual situation of palliative and supportive care services in different countries. However, there are considerable differences in such services with respect to form and number. In the United Kingdom, for example, where the terms 'palliative care', 'continuing care', 'hospice', and 'terminal care' are often used interchangeably, over 130 hospices were counted in 1992 [8, 10]. In the United States, 'hospice' now refers to the discreet form of certified terminal care provided at home or within institutions that is strictly defined, administered, and reimbursed according to a uniform set of procedures set by the government [12]. In Canada, where there are only two free-standing hospice inpatient units, 'hospice' most commonly refers to a community-based volunteer program for the terminally ill [8]. Some of the hospital-based palliative and supportive care services were first established as consultation services (e.g., at St. Luke's Hospital, New York, in 1974) and later expanded to incorporate an inpatient unit [8]. Others began by establishing an inpatient unit [9]. There are hospital-based palliative and supportive care services with an affiliated home care program [9, 13] and home care services that operate independently [14].

While circumstances such as the cultural context, local conditions and financial resources are responsible for these different developments, there are also psychological reasons. This article focuses primarily on the psychological reasons that we believe play an important role in the conceptualization and implementation of palliative and supportive care services within oncology. To illustrate our view, three different attitudes toward palliative and supportive care will be discussed.

They do not encompass the entire range of opinion about these services, but may serve to illustrate some of the psychological motives that have shaped this emerging speciality.

Attitudes towards palliative and supportive care

From our experience, three predominant attitudes toward palliative and supportive care can be identified and summarized by the following statements:

1. 'We don't need palliative or supportive care. Oncology always had to face incurable and suffering patients, and they were always treated expertly'.
2. 'Dying cancer patients have needs different from those of curable patients. We have to protect them from acute invasive medical care. Palliative care should therefore be delivered in independent settings separated from the hospital'.
3. 'All cancer patients can benefit from the aims of palliative care. In order to achieve these aims, palliative care should utilize all of the possibilities modern medicine can offer, as long as the potential benefits outweigh potential harm. To facilitate this exchange with other medical disciplines, pal-

liative care should be integrated in the general hospital. Since this approach is not reserved to the terminally ill, it should be called supportive care'.

Different motives for different attitudes

In the following we will reflect upon some of the reasons for these different attitudes and some of their consequences. The *first attitude* denies the success that centers with palliative or supportive care programmes have achieved in ameliorating their cancer patients' quality of life [15, 16]. It denies the fact that palliative and supportive care services have gained considerable recognition in recent years and are an expanding and evolving part of the medical services in most of the developed countries [8, 10, 11, 17]. Denial is the result of a threat. The threat may derive from the patient and the (often unconscious) perception of being insufficient as a medical doctor if one is not capable of facing all possible challenges, including the one presented by suffering or incurable cancer patients. By denying the possibilities palliative and supportive care has to offer, one denies one's own incompetence concerning these patients. On a more conscious level, such an attitude can also express legitimate worries about overspecialization of medicine with all of its negative impact on patient care. In addition, especially in a time of financial restriction, politically inspired motives may also play a role, since every emerging speciality in medicine is often considered a potential threat to the power of already existing specialities.

The *second attitude* acknowledges the complex needs of the cancer patients and the problem they represent for traditional curative oncology. Consequently, these health care providers wish to protect the patient from 'bad modern medicine'. They deal with this threatening situation not by denying it, but by projecting (and so diminishing and locating) the threat on medicine. On a more conscious level, such an attitude can also express legitimate worries about a medicine that has become too distant from its patients. Since some of the first models of palliative care were close to this position, it may have been necessary, as for other revolutionary movements for palliative care to first be separated from medicine in order to be re-integrated as supportive care.

The *third attitude* also acknowledges the achievements of palliative and supportive care. Different from the second attitude, this position attempts to integrate the idea of interdisciplinarity and to utilize the beneficial possibilities of modern medicine, in order to achieve comprehensive care for all cancer patients. While palliation of symptoms, either by active prevention or therapeutic intervention, remains a primary goal in this approach, it is not reserved to the terminally ill. Although this seems to be the least defensive position and the most realistic attitude, negative consequences are sometimes observed as well (see below).

Different consequences of different attitudes

All three of these positions require reflection about their possible consequences. Supporters on the *first attitude*, are probably by now a minority within oncology. In a recent survey [11] of the attitudes of the members of the physician faculty of an academic hospital in the United States where a hospice program has been in existence for more than 10 years, 96% of the respondents thought that the hospice program was a valuable resource for the medical center. Similar positive attitudes towards palliative and supportive care were demonstrated among future physicians [18]. In Britain, where an expanding number of hospices are located, only 10% of a sample of general practitioners felt no need for a hospice before one was opened in their area [10]; the number even decreased to 2% some months after its opening. While there have been no surveys assessing attitudes towards other kinds of palliative or supportive care services, these three surveys indicate that attitudes among physicians with direct clinical experience with such services are positive. Physicians who are still opposed to these ideas will now miss the opportunity to integrate palliative and supportive care into their services. They will soon have to face severe criticism from colleagues and the public, since dissatisfaction with hospital services and satisfaction with palliative and supportive care services among referring physicians, patients with advanced disease and their relatives have already been documented [11, 19]. In a time of increased regard for the patient's point of view and patients' rights [20], and a time of increased awareness within medicine of the limits of biomedical results, and a commitment to the broader perspective of quality of life [1-3], this position will probably not survive. In the meantime, it empowers those who accuse medicine of not taking care of their patients.

Supporters of the *second attitude* are those who feel uncomfortable about the increasing technological aspects of modern medicine and who alienate themselves by creating alternative forms of health care. One consequence is that their patients do not benefit from the tools for symptom control that medicine has to offer. It is generally accepted that effective symptom control is best offered when palliative and supportive care is delivered within a hospital or at least within a medical setting [8, 11, 21]. Another consequence could be that their alienation would lead them to indoctrination by extreme groups who oppose the present medical system. In some countries, such as Switzerland, proponents of physician-assisted suicide have tried to open independent 'health care' structures to pursue their goals. An increased empowerment of these movements by traditional health care providers would have considerable and dangerous consequences for the care and the rights of the weak and incapacitated members of our societies [22].

Supporters of the *third attitude* are situated in the mainstream of supportive care. At first glance, there

may seem to be no harmful consequences to fear from such a reasonable point of view. However, in palliative care settings that try to integrate the investigation and methods of modern medical treatment, there is a temptation to utilize these tools for goals other than medical ones. They can be used for action when reflection is required or they can be used to test the performance of palliative care as a future subspecialty. A failure to understand the differences between symptoms and suffering increases the likelihood of such misuse. While symptoms can be controlled by medical interventions, suffering is part of the human condition, and can not be controlled by medication, radiation or surgery. If the wish for medical omnipotence demands the illusion of control of suffering, suffering is reduced to a pathological process and medical interventions will replace and prevent empathy, compassion and care [23]. Such risks are especially represented in cultures where paradigms like activism ('we can and should shape the future') and positivism ('this future will certainly be better than the present') are dominant [24]. There, the famous 'war on cancer', already implying an extremely aggressive conflictual situation, can easily expand to 'a war on incurable cancer', which would certainly also leave victims behind.

Conclusions

While there are always rational arguments for one or the other point of view, it should not be overlooked, that there may also be unconscious or otherwise hidden factors influencing the discussion of palliative and supportive care. In the face of the spreading movement for palliative and supportive care, it is in the interest of health care providers within oncology to reflect upon and discuss the different attitudes towards its implementation, and the interrelations between these attitudes, the cancer patients and themselves. We agree with those who maintain that the goals of palliative and supportive care are best served when such services are integrated in teaching hospitals and into other medical settings [8, 11, 18]. The integration of such services seems to be most effective where psychological barriers to the implementation of palliative or supportive care are kept to a minimum. This can be achieved when a credible and effective team within the hospital takes the leadership for implementation or if the dialogue about such services takes into account the psychological motives for the different attitudes. From our experience, the former approach is usually more promising.

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