



**Ethical Dilemmas
in Hospice and Palliative Care Units
for Advanced Cancer Patients**
İleri Evre Kanser Hastalarına Yönelik
Hospis ve Palyatif Bakım Ünitelerinde Etik Sorunlar

Beyhan Bağ¹, Nesrin Reis²

¹Psychiatry Nursing, Giessen, Germany

²Bezmialem Vakıf University, Istanbul, Turkey

ABSTRACT

Ethical dilemmas that face healthcare team members referring patients to hospice programs include the ability of clinicians to predict accurately a patient bad prognosis. They affect day-to-day patient management in palliative care programs including healthcare team members concern over the use of morphine because possible respiratory depression in the patient, the question of providing enteral or parenteral nutritional support to patients who refuse to eat and the question of providing parenteral fluids to patients who are unable to take fluids during the terminal phases of illness. A final ethical dilemma concerns the methodology for quality of life research in palliative care. Understanding and resolving these ethical dilemmas is an important factor determining the quality of the caring for the patient. The ethical dilemmas that are discussed in the article likely to occur in this period can be prevented through his/her participation in the decisions concerning his or her treatment.

Key words: End of life, ethics, hospice care, palliative care, cancer

ÖZET

Palyatif ve hospis programlarında bulunan hastalarla ilgili sağlık personelinin karşı karşıya kaldığı etik sorunlar çoğunlukla hastanın kötü prognozuyla ilişkilidir. Bu programlarda bulunan terminal dönemdeki kanser hastalarıyla ilgili olarak sağlık personelinin günlük olarak karşı karşıya kaldığı etik ikilemler arasında morfin uygulamaları, oral yolla beslenmesi mümkün olmayan hastalar için enteral ve parenteral beslenmenin hasta tarafından ret edilmesi sayılabilir. Ayrıca bu hastalarda yaşanması



olası diğeri bir etik ikilem bu merkezlerde bulunan hastaların yaşam kalitesi düzeyleridir. Tüm bunlar, bu merkezlerde terminal dönemdeki kanser hastalarının bakım ve tedavisinden sorumlu sağlık personelinin karşılaşılabileceği etik sorunlardan sadece bazılarıdır. Yaşanılması olası bu etik ikilemlerin sağlık personeli tarafından anlaşılması ve çözüm önerilerinin getirilebilmesi tedavi ve bakım kalitesini artıracaktır. Nitelikli palyatif ve hospis bakım merkezlerinin ana hedefleri arasında hastalara yaşam kalitesi yüksek bir bakım sunarak huzurlu bir ölümün sağlanmasıdır. Bu yazıda sözü edilen sağlık personelinin terminal dönemdeki hastalarda karşılaşılabileceği etik sorunların hastaların kendileriyle ilgili tedavi ve bakım kararlarının katılımlarının sağlanmasıyla önlenebileceğini düşünüyoruz.

Anahtar kelimeler: Yaşam sonu, etik, hospis bakım, palyatif bakım, kanser

Introduction

Being at the end of life is probably the most difficult experience for cancer patients, their relatives and dears as well as for the oncology professionals providing care to them. It is in this period that difficult decisions, such as active or palliative care, death at home or hospital, are to be made¹. The health caregiver, either in a home, in a hospice or in palliative care service, in order to maintain the quality of life of the patient with cancer in an advanced stage, on the best possible level will be faced with ethical dilemmas during the care and treatment process.

As people with advanced cancer approach the death itself, they often need symptom relief. Symptom distress refers to the amount or level of physical or mental upset, anguish, or suffering experienced by a person with a specific symptom². Most patients, as they near death, contend with similar fears, needs and desires. Dying patients experience fear of pain, fear of indignity, fear of abandonment and fear of the unknown³. Hospice and palliative care provision is acknowledged to be a priority in the development of comprehensive health care services, particularly where there are high rates of mortality from cancer and consequently need for skilled supportive care, pain management, and symptom control at the end of life⁴.

Palliative care has been practiced for thousands of years, but only since the founding of the modern hospice movement by Dame Cicely Saunders in 1967 has it gradually been identified as a special practice⁵. Palliative care refers to patient- and family centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice⁶. At its best, palliative care almost always requires an interdisciplinary approach. It emphasizes

scientific accuracy and the best traditions of medicine: kindness, respect of person, setting goals, compassion, empathy and non abandonment. In short, it is total care. It embodies the essence of excellent medical care. But, because it includes much of what has become hospice care practice and philosophy, it has come to be identified with end-of-life care.

On the other hand, hospice care provides humane and compassionate care to people in the last phases (they do not have more than 6 months, or about 180 days, to live) of incurable cancer so that they may live as fully and comfortably as possible. Hospices provide a range of inpatient, day and outreach services for dying people⁷. The hospice philosophy recognizes death as the final stage of life and seeks to enable patients to continue an alert, pain-free life and to manage other symptoms so that their last days may be spent with dignity and quality surrounded by their loved ones. Untreatable cancer causes death within weeks or months and the pain may be even more difficult to control. Hospices form a specific environment for dying people or their families in providing several important aspects of care. For those people who are about to complete their life's journey, a hospice is a place where they will not only get rest and be autonomous in making their own informed decisions, but also where they may feel safe and find shelter.

Palliative care centers and hospices face some problems and ethical discussions when dealing with patients with cancer in its advanced stages. Understanding and resolving these ethical dilemmas is an important factor determining the quality of the palliative care for the patient. This article discusses the possible problems and ethical dilemmas that might emerge in two health institutions.

The Needs of the Advanced Cancer Patients in Hospice and Palliative Care Units

Palliative care is the physical, psychological, social, and spiritual care provided to patients from diagnosis to death or resolution of a life-threatening illness. Hospice care is a comprehensive program of care that is appropriate when patients with chronic, progressive, and eventually fatal illness are determined to have a prognosis of 6 months or fewer. Death at home has been associated with availability of hospice programs and whether or not the hospice is hospital based or home care-based⁷. Palliative medicine as practiced in hospices and palliative care units are usually defined as total and continuous care for the patient and his family when the disease does not react to curative treatment and death becomes inevitable⁹.

The patient rapidly experiences losses in self-sufficiency in the hospice or the palliative care unit s/he is staying at. For example, the patient cannot perform the daily activities which had been a part of her/his life prior to the disease. The patient, even with pain, who is losing the ability to drive a car or to have sex with his partner may have a great need of different treatment, or a different approach that may prevent, delay or minimize his / her losses¹⁰. Because of the physical symptoms (vomiting, pain, nausea) s/he is experiencing, a continuous treatment is required. The patient did not only transform from an independent and healthy individual to a sick one but her/his life-span is now measured by months and days. For the cancer patient who is living the last periods of her/his life, a complex psychological process has begun. When the whole process the patient is experiencing is taken into consideration, palliative medicine as it is practiced in hospices and palliative care units has to manage integrally at all the patient needs. Decisions making should always contain all the elements: prevention of loss, symptom control, and spiritual care.

Difficulty of Research in the Palliative Care Settings and in Hospices

Palliative and end-of-life care faces a difficult problem. Although this newly recognized subspecialty, like all of Medicine, depends upon clinical trials to advance the evidence base underlying practice and to demonstrate strategies to improve outcomes, a host of historical barriers impede research. Logistical challenges, such as recruitment and retention in a fragile population with poor prognosis, pose a certain level of impediment, but perhaps the thorniest barriers to research in the end-of-life setting are those surrounding the ethics of conducting research with human subjects in this population ¹¹.

The field of palliative medicine has made a concerted effort to increase research productivity and to disseminate findings. Several palliative care–specific peer-reviewed journals, as well as general medical, nursing, and social work journals, now publish an increasing number of studies of relevance to end-of-life care, yet the bulk of these publications report on case series, nonrandomized trials, or studies of low methodological quality; few are randomized clinical trials ¹². It is clear that palliative care and treatment should be improved for the patients with cancer in its advanced stages in hospices or palliative care units. However, research that involves patients near the end of life creates numerous ethical challenges. The dilemma is this: whereas a central goal in the conduct of modern research is to protect vulnerable research participants and the dying are perceived to be especially vulnerable, a central goal of

palliative care is to improve the care of patients as they approach the end of life. Conducting research in this population is an important strategy for meeting that goal. Is it possible to satisfy both goals? The success of an evidence-based practice of palliative care depends on public understanding and acceptance of research. Therefore, investigators can and should ensure that this area of potentially controversial research adheres to the ethical standards and procedures of other fields. They must also ensure that planned research is consistent with patients' preferences and expectations.

Palliative Sedation: To Patients with Advanced Cancer as an Alternative to Hasten Their Death

The vast majority of patients treated in hospices or palliative care units throughout the world suffer pain due to advanced disease; most being cancer sufferers. Untreatable cancer causes death within weeks or months and the pain may be even more difficult to control. One of the most significant concerns among dying patients and their families is the fear of uncontrolled pain during the dying process. The cancer patients in the last stage of their lives receive palliative sedation for pain release. Cicely Saunders, the founder of the modern hospice movement, prefers to use the expression "aggressive palliation". Afterwards, this concept has been renamed many times as "terminal sedation"; "sedation for intractable distress in the dying", "palliative sedation", "palliative sedation therapy", "end-of-life sedation"¹³⁻¹⁷.

All these concepts define preventative applications which relieve symptoms of patients with terminal illnesses. Palliative sedation refers to the use of medications to induce decreased or absent awareness in order to relieve otherwise intractable suffering at the end of life. Treatment and relief of refractory symptoms is its sole purpose. The patient dies of his or her disease. The benefit of relief of symptoms far outweighs the adverse effect of the sedation. This is adequate justification for this intervention. However, the discussion is complicated by consideration of death as the bad effect. This treatment is almost always accompanied by a discussion of the 'rule of double effect' (RDE). The RDE is invoked when the act has two effects/ the intended good effect/relief of suffering and an unintended or bad effect/unconsciousness or death. When sedation is resorted to for relief of symptoms, the intend good. Death should not occur except when due to an idiosyncrasy, carelessness, accident or intention¹⁸. The desired outcome of palliative sedation is relief of patient suffering through sedation, with the possible risk of hastening death. However, studies have affirmed

that a very small minority of patients sedated at end of life experience life-threatening untoward adverse effects such as aspiration or respiratory depression¹⁹. Furthermore, recent prospective and retrospective data suggest that in the overwhelming majority of patients, palliative sedation at the end of life does not hasten death^{19,20}. Palliative sedation is a clinical procedure aimed at relieving refractory symptoms in patients with advanced cancer. A study suggested that even if there is no direct evidence from randomized clinical trials, palliative sedation, when appropriately indicated and correctly used to relieve unbearable suffering, does not seem to have any detrimental effect on survival of patients with terminal cancer. In this setting, palliative sedation is a medical intervention that must be considered as part of a continuum of palliative care²¹.

The European Association for Palliative Care (EAPC) considers sedation to be an important and necessary therapy in the care of selected palliative care patients with otherwise refractory distress. Prudent application of this approach requires due caution and good clinical practice. Inattention to potential risks and problematic practices can lead to harmful and unethical practice which may undermine the credibility and reputation of responsible clinicians and institutions as well as the discipline of palliative medicine more generally. Procedural guidelines are helpful to educate medical providers, set standards for best practice, promote optimal care and convey the important message to staff, patients and families that palliative sedation is an accepted, ethical practice when used in appropriate situations²².

Palliative sedation has an important place on the continuum of appropriate palliative care at the end of life. It is not hastening death. The intent is different. It is appropriate therapy for refractory and unacceptably severe suffering. As with any other therapy, the patient or surrogate should be informed of potential adverse effects, including loss of social interaction and potential for life-threatening aspiration or respiratory depression. Palliative medicine teams should be involved, if possible, in any case in which palliative sedation is considered. Institutional lack of palliative medicine availability should not preclude the use of palliative sedation when appropriate²².

Artificial Nutrition and Hydration at the End of Life in Cancer Patients

Withholding fluids and/or nutrition can raise special ethical concerns for many who consider the provision of food and hydration as a basic human need, fundamental to the care and respect of the patient. Family members may be concerned about discomfort that they assume

occurs when food or hydration is withheld²³. Cochrane reviews have been published on the effects of medically assisted hydration and nutrition in adult patients receiving palliative care, including the terminal and dying phase. It was concluded that the currently available evidence is insufficient to make any recommendations for practice with regard to the use of medically assisted nutrition and hydration in patients receiving palliative care^{24,25}.

Not only do anorexia and weight loss produce physical changes, but also these symptoms are perceived by patients and families as a sign of deteriorating health. This has the additional effect of producing significant anxiety. Aggressive nutritional support in cancer patients with either parenteral or enteral nutrition has met with little success. Every effort should be made to make food available and attractive for patients. Dietitians and food servers may go to great lengths to achieve this. Because food is more than nutrition, it becomes an important part of comfort care. Even ineffective nutrition support can be seen as a means of keeping hope alive; however at some points, the feeding process itself can become a burden to a patient. When feeding becomes a burden to a patient, it is extremely important to recognize that aggressive nutrition support, whether by tube feedings or parenteral feedings, is a medical treatment and should be treated as such. As with any intervention, goals must be established. And if these goals cannot be achieved, the intervention should be withdrawn²³.

Recent studies have demonstrated that, in debilitated patients, enteral feedings by either nasogastric tube or percutaneous gastrostomy are associated with significant morbidity and mortality²³. Although it may be very appropriate to provide enteral nutritional support to selected patients with advanced cancer, who are unable to eat because of tumor obstruction of the upper gastrointestinal tract, it certainly appears that for the majority of advanced cancer patients who are debilitated and have decreased dietary intake because of the overall effects of their illness, the potential risks of enteral nutrition outweigh any benefit. There are many other simple and often overlooked treatments that can be recommended to patients in dealing with anorexia^{26,27}.

The management of hydration in patients at the end of life has become a controversial issue. Routine practice varies from almost universal intravenous hydration in acute care settings to complete avoidance of hydration in some palliative care programs. Several authors have previously outlined positions, both clinical and ethical, in support of and against hydration in terminally ill patients²⁸⁻³⁰. Physicians and other health care providers are concerned about

symptoms such as patient discomfort caused by thirst and a dry mouth, and yet at times it appears that the provision of parenteral fluids at the end of life is of more therapeutic benefit to the doctors and nurses caring for the patients than it is for the patients themselves. Near the end of life, fluid needs decrease and it is more difficult for the body to properly mobilize and incorporate the fluids that are provided. Significant third spacing of fluid can often be the result, leading to increased edema, increased pulmonary and gastrointestinal secretions, and probably more rather than less patient discomfort.

No controlled clinical trials addressing the potential benefits and risks of intravenous hydration in patients at the end of life have been performed. However, the current physiological evidence would certainly suggest that for the patient, pleasure in drinking and mouth care are the overriding concerns and that because of the potential for causing further patient discomfort by having fluid accumulate in the lungs and gastrointestinal tract routine, parenteral hydration should be avoided near the end of life in favor of liberally providing patients with small amounts of fluids and ice chips, and providing meticulous mouth care. In the case of law, artificial hydration has been considered a treatment and, as such, governed by the same legal and ethical principles of withholding or withdrawal³¹. Discussion surrounding hydration must take into account the emotions and religious beliefs attached to this issue. Although the discourse is rarely neutral, it can strive to be explanatory and place these interventions into the context of the overall goals of care. Raijmakers et al. carried out a literature review on the use of artificial nutrition and hydration in the last days of life of cancer patients³². They suggested that although the effects on comfort, symptoms and length of survival seem limited, it will be providing artificial nutrition and hydration to cancer patients who are in the last week of life is a frequent practice.

Professional caregivers working in palliative care and hospice centers have been shown to be more reserved about the benefits of artificial nutrition and hydration than other professionals: most of them do not believe that they contribute to the alleviation of symptoms and many are concerned about the burdens of artificial nutrition and hydration in the last week of life^{33,34}. On the other hand, terminal patients and relatives often have a positive attitude towards hydration in the last week of life and often perceive artificial hydration and artificial nutrition as clinically useful standard care at the end of life^{35,37}. Whereas shared decision making is considered standard practice in modern end-of-life care, such positive attitudes of patients and relatives most likely influence the practice of providing artificial nutrition or artificial

hydration, despite limited evidence of their effectiveness. Professionals therefore should communicate clearly with patients and relatives about the limited evidence of beneficial effects of artificial nutrition and artificial hydration^{38,39}.

Withholding or Withdrawing Treatment

With modern medical therapies life can often be significantly prolonged. Yet, sometimes in cases of severe illness and advanced disease a patient and his or her caregivers may be confronted with the question whether curative or life-sustaining treatment is still worthwhile. They may be of the opinion that the proposed treatment will not have the desired outcome or the side-effects of the treatment will outweigh the benefits. Decisions to withdraw treatments must be explained to relatives and carers, who may otherwise interpret that it was the lack of these measures that caused death (rather than the underlying disease)⁴⁰. Therefore Patients and caregivers will have to decide whether they will initiate or withhold, continue or withdraw the treatment. Even if the caregivers want to administer the treatment, the patient may still refuse the therapy. When discussing treatment options with patients, it is important to give a balanced view and to explain clearly what the plan of care will be if it is decided to withdraw or withhold treatment. If this information is not given, the patient may opt for treatment because of false hope, or from fear of abandonment by health-care professionals.

Are Patient-Generated Data the Only Valid Method of Measuring Quality of Life Outcomes in Palliative Care Units and Hospices Research?

In 1990, the World Health Organization noted that "the ultimate goal of palliative care is the achievement of the best quality of life for patients and their families." Quality of life (QOL) serves as the final common pathway for palliative care services⁴¹ and should be considered as the main outcome measure⁴². Measuring patients' QOL is essential so that aspects requiring intervention and counseling can be identified, and the benefit of care and treatment can be assessed⁴³. There is now considerable research on QOL and quality of palliative care, but the experiences of patients at the very end of life have not been adequately addressed⁴⁴. Patients with cancer enter treatment with the goal of care However, for some, that goal is not met,

and they must face the reality of a life-limiting illness. As the disease progresses, symptoms often mount and quality-of life (QOL) issues become paramount.

While there is agreement that this is certainly preferable, a major challenge in palliative care settings is that, especially in the last days of life, alterations in patients' mental status or level of consciousness often prevent investigators from obtaining these patient-generated data. Excluding patients who are physically or cognitively impaired creates a major dilemma, because this is the very group of patients where most of the questions regarding the efficacy and appropriateness of palliative care interventions arise, the needs of these patients may differ significantly from those who are alert enough to provide their own data^{23,45}. Therefore, it is critically important for investigators who are doing palliative care and hospice research to recognize the importance of developing alternative methods of measuring quality-of-life parameters in those patients who are not physically or mentally capable of providing their own input. The ethical question here is whether or not the person is facing his death peacefully. Questions to ask include the following:

Was the place of death the one the patient had chosen?

Was there anybody with the patient when he died?

Did the patient tell anybody he was facing his death peacefully?

Was the patient in pain during the last hours of life?

Was the patient with dyspnea (if conscious) during the last hours of life?

Was the patient vomiting during the last hours of life?

Did the patient need pharmacological sedation during the last 12 hours?

Was any life-saving procedure applied?

Before death, were religious or secular rituals fulfilled?

Did the family get in touch with the palliative care team immediately after the patient's death?⁴⁶

The Morality of Euthanasia

Euthanasia is defined as the physician's intentionally administering a treatment (usually medications) to cause the patient's death, with the patient's full, informed consent. The current debate is modulated by the acceptance of withholding and withdrawing life-sustaining therapies and the need to set limits on their use. Other influences include the self-determination movement, the promotion of choice in decision making at the end of life and changes in social values⁴⁷.

Research suggests that patients who are in the last year of life fear dependency more than they fear pain, and these fears make them more likely to ask for euthanasia. A survey of the recently bereaved, who commented upon the last years of life of a close friend or relative, found that pain was only weakly linked to requests for early death. Perceived or real dependency was the main reason for expressing a wish to die earlier⁴⁷. These researchers suggested that the study had important implications for the hospice movement which now needed to extend the expertise developed in the area of symptom control, to addressing the problem of dependency.

Mak and Elweyn⁴⁸ conducted a hermeneutic study with unstructured interviews to explore the meaning of desire for euthanasia in six patients with advanced cancer who had expressed a wish for euthanasia while receiving palliative care. They found five main themes: the reality of disease progression, perception of suffering, anticipation of a future worse than death, desires for good quality end of life care, and presence of care and connectedness. Thus, meaning of desire for euthanasia was not confined to physical and functional concerns but revealed hidden psychosocial and existential issues, understood within the context of the patients' whole life experiences. The patient who requests termination of life because of suffering is actually crying out for help. Most of these requests disappear when the symptoms are properly addressed and the patient is reassured that pain and suffering can be relieved. Those who persist in these requests and believe they have a right to die are often suffering from depression or other psychological illnesses.

Modern palliative care and pain relief are real and available options in many countries. They have been proven to be effective in the relief of suffering and in assisting the process of dying. Euthanasia should not be perceived as an alternative to the advantage of the developments in

hospices and palliative care units where a care in order to provide a high quality of life is given to patients in the last stages of their lives.

Conclusion

Clinical knowledge about harms and benefits is necessary for healthcare team to practice competently. There are codes, position statements, principles, research findings, similar cases, and resources available to assist in conflict resolution. However, every situation is unique and must be treated in context while respecting boundaries provided by the law and professional ethics. Healthcare team members may not have answers for the existential questions of life and death any more than the dying person does. They may not be able to assuage all feelings of regret or fears of the unknown. But it is not our salutations that matter. The role of the clinical team is to stand by the patient, steadfastly providing meticulous physical care and psychological support, while people strive to discover their own answers. The task or duty of the hospice/palliative care units and the staff charged at these units and serving the patients nearing the end of their lives is to control the symptoms disturbing these patients and provide a safe and peaceful moment of death. The ethical dilemmas likely to occur in this period can be prevented through his or her participation in the decisions concerning his or her treatment.

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Correspondence Address / Yazışma adresi:

Beyhan Bag
Department of Psychiatry Nursing
Giessen-Germany
e-mail: beyhanbag@yahoo.com