Journal of Intercultural Management and Ethics

JIME

ISSN 2601 - 5749, ISSN-L 2601 - 5749

published by

Center for Socio-Economic Studies and Multiculturalism
Iasi, Romania
www.csesm.warter.ro

Special Editor

Professor Beatrice Gabriela Ioan, PhD, MD
Grigore T.Popa University of Medicine and Pharmacy of Iasi, Romania
E-mail: ioanbml@yahoo.com

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ETHICAL ASPECTS AND MECHANISMS OF PSYCHOLOGICAL ADAPTATION IN CASE OF PATIENTS DIAGNOSED WITH INCURABLE DISEASES

Andreea Clim
”Grigore T. Popa“ University of Medicine and Pharmacy, Iasi, Romania
Department of Morpho-Functional Sciences II
E-mail: andreea.clim13@yahoo.com

Minela Aida Mărănducă
”Grigore T. Popa“ University of Medicine and Pharmacy, Iasi, Romania
Department of Morpho-Functional Sciences II
E-mail: sminelaaida@yahoo.com

Nicoleta Dima
”Grigore T. Popa“ University of Medicine and Pharmacy, Iasi, Romania
”Sf. Spiridon“ Emergency County Clinical Hospital, 3rd Medical Clinic, Iasi, Romania;
E-mail: nicoleta2006r@yahoo.com

Roxana Gănceanu Rusu
”Grigore T. Popa“ University of Medicine and Pharmacy, Iasi, Romania
”Sf. Spiridon“ Emergency County Clinical Hospital, 3rd Medical Clinic, Iasi, Romania;
E-mail: roxanarusu12@yahoo.com

Ioana Adelina Clim
”Dominic Stanca“ Clinic of *Obstetrics*-Gynecology, Cluj-Napoca, România
E-mail: clim.adelina@yahoo.com

Ionela Lăcrămioara Șerban
”Grigore T. Popa“ University of Medicine and Pharmacy, Iasi, Romania
Department of Morpho-Functional Sciences II
E-mail: ilserban1@yahoo.com

Abstract

The term *palliative care* refers to the care of people with advanced disease and minimal chances of survival. Palliative care alleviates the inevitable symptoms, accepting that the disease can no longer be treated, being a holistic approach. In addition to medical care, it provides emotional and religious support, preparing and counseling others for irreparable loss. This change of approach accepts that death is predictable and inevitable. The principles of medical ethics, the cultural, religious and philosophical belief of patients as well as the limitation of medical science have a decisive role among these patients.

Keywords: incurable disease, palliative care, ethical aspects, death.

Introduction

In the last decades, although considerable progress has been made in the care and treatment of oncological pathology, palliative care and the subject of death have been and continue to be controversial topics at the center of ethical debates and at the same time one of the most „sensitive“ topics to be addressed (Breslin et al., 2005). The subject of death is „looked at“ differently depending on the culture of the population. In Western culture, death is a sensitive problem that is often spoken of through metaphors („went away from us“, „it went beyond“). In Eastern culture, death is not seen as a purpose, but as a new beginning (Omer, 2010).

Palliative care services are a major public health problem worldwide due to the demographic explosion and the large proportion of the aging population, diagnosed with incurable diseases and multiple comorbidities (Higginson, Davies & Tsouros, 2007; Stjernswärd, 2007).

The World Health Organization (WHO) defines palliative care as „actions taken to improve the quality of life of patients and their families, by preventing and ameliorating suffering, by identifying early and by correctly evaluating symptomatic treatment, but also by solving other problems: physical, psychosocial and spiritual“ (Olăroiu, 2018).

Palliative care values life and considers death a natural process. Palliative care cannot remove all suffering, but it can improve the quality of life of the patient to its end. By effectively alleviating suffering, at a relatively low cost, palliative care is not reduced to end-of-life care, as it has been proven that early initiation of palliative care improves quality of life and reduces the need for difficult and aggressive treatments. Thus, palliative care is increasingly recognized as an important part of the continuity of the care process, both for cancer patients and those with non-oncological diseases, such as HIV and TB patients or patients with cardiovascular pathology (Olăroiu, 2018). Palliative care is a holistic approach to medicine and managing terminal illnesses can often be a challenge both for the patient, his/her family and for the medical staff, being performed within an interdisciplinary team (to meet the complex needs of the patient and family), at the center of it being the patient with his/her family. The members of the interdisciplinary team interact with both the patient and his/her family, but also with each other, depending on the complexity of the case or the evolution of the disease: the doctor, the medical assistant, the social worker, the nurse/home care worker, the psychologist, the priest/pastor, the physiotherapist, the occupational therapist, the game therapist, the dietitian, the pharmacist and, last but not least, the volunteers. The role of the medical team is to respect the essential ethical principles in palliative medicine, ensuring the patient the quality of life and respecting the dignity of the human being until the last moment, making decisions regarding the patient, together with him/her and not on their behalf (Olăroiu, 2018).

Physician/medical team-patient relationship in palliative care

Of the ethical principles, unanimously accepted (autonomy, beneficence, non-maleficence and justice) in the medical decision-making process the emphasis is placed on autonomy (especially in the Western countries). In order to make a decision, patients must receive and understand correctly the information about their health condition and prognosis, the type of treatment proposed, therapeutic alternatives, their risks and benefits. Therefore, adequate information is considered one of the patient’s right.

An important concept that might be of paramount importance in the decision-making process concerning healthcare is that of futility. Futility can be evaluated from either qualitative or quantitative perspective, being based on two notions: the life span and the quality of life. The issue of quality of life, purpose, human dignity, impact of quality of death and spiritual support in patients diagnosed with incurable diseases have always been problems of medical ethics (Petruţa, 2014).

Quality of life is described as a multidimensional, evaluative concept represented by the resultant relationship between living conditions and activities that make up human life, aspirations, values and human needs, referring both to the objective conditions in which human life is constituted and to those topics (happiness, fulfillment and satisfaction) (Petruţa, 2014).

The quality of life for oncological or non-oncological patients can be assessed by taking into account five components: mental status (normal/abnormal), physical condition (autonomous/moderately dependent/totally dependent), social condition (integrated/isolated), intensity of pain (without pain/minimal pain/moderate/severe) and the presence of depression (no depression/moderate or severe depression) (Curtis & Burt, 2007). It is also necessary to take into account the fundamental legal principles: the respect of life will have to be replaced by references to the quality of life; the notion of human dignity will have to be replaced by that of the freedom to dispose of one's own life and to assess for oneself whether it is worthy/unworthy to live in certain conditions (David & Năstase, 2012). This last aspect is particularly sensitive, the quality of life being perceived differently from a legal, cultural or even personal point of view. Until the patient comes to consider death as a natural event, the pre-depression feelings that include anxiety, fear and sadness will always affect him/her, unless the advice of qualified staff to suggest a potential problem solution is accepted.

The doctor has the professional and moral obligation to identify the therapeutic options that promote the patient's well-being. It is prohibited performing or omitting acts that harm the patient (not only as adverse effects but also morally). The medical truth must be communicated with sensitivity, tact and sincerity. By virtue to its autonomy, the competent and well-informed patient may decide on a particular therapeutic option or refuse any treatment.

The duty and especially the purpose of the physicians is to be in the service of life until its end; the patient lives even when he/she is in the terminal stage of his/her physical life (Puchalski, 1994). It is the moral duty of the physician to show compassion, understanding, towards the patient in the terminal stage of life and towards his/her family, giving them all the needed emotional support. The treatment offered to the patient must be multidisciplinary and adapted to his/her specific needs.

The death of the human being must be a worthy one, without unnecessary torment, in comfort and peace, when all the dynamic assessments prove the uselessness of any medical act, regardless of how well-intentioned and sustained it may be. Deciding whether or not to administer parenteral nutrition and hydration, discussing non-resuscitation are some of the key issues that clinicians face in such situations.

Although the fundamental ethical principles underlying palliative care are focused on the highest quality of life of the patient and his family, there are situations in which they do not benefit, causing ethical problems regarding the differences between the patient's desire and the opinions of the medical team. It has been claimed that therapeutic decisions in certain situations are unnecessary and often costly (Kellehear, 2000). Although each health system faces the problem of cost coverage and cost-effectiveness, in palliative care the moral, ethical, humanitarian and clinical aspects are often a controversial topics (Kovacs, 2014).

The advanced planning of medical care should be a priority in the development of medical services for patients with incurable, oncological or non-oncological diseases, regardless of age or prognosis. The purpose of care and treatment in end-of-life situations is to prolong life and add quality to it. The multidisciplinary team must include physicians, psychologists, nurses, social workers, physiotherapists, clerics. The patient care team must agree on the profile of the help they provide with the patient's stage: denial and isolation, anger, negotiation, depression or acceptance.

Alleviating the suffering, obtaining the necessary minimum autonomy as well as emphasizing the improvement or maintaining the quality of life as well as awareness of the possibility of death are the main objectives of the healthcare provided to these patients

(Fritsche & Girardot, 1992; Smith & Cassel, 2009; Carrieri, Peccatori & Boniolo, 2018). Differentiating between the subjective and objective elements of quality of life is sometimes difficult to draw, being determined by the methodological problems of the measurement, since the affective states and the cognitive distortions lead to varied evaluations of the same objective situations.

Psychosocial aspects

The mechanism of psychological adaptation in the case of the patient diagnosed with an incurable disease is a complex, long-term process, requiring a holistic approach of the person (physical, social, mental and spiritual). Each person has his/her particularities and his/her pace of adaptation at the time of diagnosis. Most patients and their families need time to understand and adapt to the changing reality of imminent death (Mularski et al., 2005).

The attitude „towards death" depends largely on the culture to which the person belongs. From a medical point of view, death is seen as the last phase of life, when any cardio-respiratory and cerebral activity ceases. At the same time, death can be „regarded" as a mystery, as „the last term" or as a natural thing, but also as a punishment (Larcan, 1992).

Emotional reactions after the communication of sad news are influenced by the personality of the patients, their age and social support and also by the stage, location, symptomatology and prognosis of the disease. According to the criteria described by Kubler-Ross the emotional reactions range from denial, anger, negotiation to acceptance and adaptation (Badiu, Neghirlă & Horváth, 2004). The most important stage is the acceptance of death by the patient.

The evolution of the disease can make physical suffering difficult to endure, which is why the medical team must look for appropriate individualized solutions, including supportive psychotherapy which must be accepted by both the patients and his/her family, that can ease the patient's suffering. The family plays an important role in improving the last moments of the dying patient's life. Thus, the support must be both from the medical team and from the family, all having the same purpose: improving the quality of the patient's life. Anxiety and depression are the most important emotional reactions experienced by the terminally ill patients, often associated with the progressive deterioration of their health. The expression „preparatory depression" means the acceptance of the terminal stage of the disease, often the patients reaching despair, becoming withdrawn and isolated when they are most in need of help.

Depressive-anxiety symptoms negatively affect quality of life of the patients with oncological pathology, these being considered as a complication of the somatic disease, an aggravating factor or a coincidence, both by the impact of the symptoms themselves on the socio-occupational functionality, as well as by the psychological impact of the cancer diagnosis. The psychological impact is characterized by lack of hope, ideas of guilt, fear of death, alteration of the personal image, decreased social support, and discomfort pain in the final stages of the disease. Assessing depression in cancer patients is difficult, often burdened by uncertain boundaries between subclinical and clinical non-pathological forms of depression. Denial of the truth, anger over the situation that cannot be controlled, followed by negotiation, if anything could be done, then slipping into depression, in the event of therapeutic failure or even death is the path that is passed by patients with a diagnosis hard to accept.

Literature data shows that older people are quicker to accept death, even if they are not sick or suffering.

In the case of young adults, the dominant feeling is anxiety, but the mechanism of adjustment occurs faster. The wisdom of living life helps each one to look back contemplatively and acceptance becomes necessary for a death in peace with yourself and those around you. The patient's life changes suddenly and the transition from the logic of life to the logic of survival becomes essential. The most important aspect is the confidence of the patient in the medical team to maintain the best quality of life possible. The role of the medical team is to ensure that patients have access to a wide range of assistance to solve the complex challenges of palliative care. This includes emotional and psycho-social assistance, clinical recommendations and management of symptoms, such as pain. Indeed, for many patients and their families, the emotional impact of a terminal disease is a real challenge in daily practice.

Spiritual support

Another important aspect in the end-of-life care is the spiritual support, which can have multiple forms, from a spoken prayer or a Bible reading done by the patient's close friends or a member of the hospital staff or a volunteer to the administration of the sacraments, depending on the patient's own religious orientation and his/her own sensitivity. To accompany a patient to death in a humane and professional way, possibly investing any gesture with religious significance that any work and any act of solidarity can have, means to truly respect his/her dignity and to recognize the beauty of life until its end.

In the face of death, hope seems to diminish, but despair can be avoided. At the same time, spiritual concerns may become more intense as death approaches and spirituality may improve significantly the patient's quality of life (Larcan, 1992). Through assessment and intervention, family or caregivers can find relief and the power to move on (Badiu, Neghirlă & Horváth, 2004).

The dying person can seek deeper spiritual meanings of life, relationship with others and with God. Assessing the meaning of „hope“ for a person helps the patient and family set realistic goals for the remaining period.

Conclusions

Palliative care is an approach designed to improve the quality of life of patients and their families, to deal with problems caused by incurable diseases with limited prognosis. Palliative care focuses on the prevention and alleviation of suffering, by early identification, assessment and treatment of pain and other physical, psycho-social and spiritual problems.

The quality of life in relation to health includes both positive and negative aspects of physical and mental health. These are directly proportional to the quality of health care, determined by the professional quality of the health services, and patient satisfaction.

Palliative care remains an essential, indispensable, full, active component of the care of terminally-ill patients and their families, usually when the disease no longer responds to the curative treatment, even if it was initiated in the early phase of the disease.

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