




Medical ethics in pain and palliative medicine

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INTRODUCTION

Palliative Medicine/Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (1).

The focus of Palliative medicine is: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (2, 3).

It starts when traditional methods of treatment are exhausted or when the signs of the spread of malignant disease reached such a degree that it is difficult for the patient to cope with them. The three most important focus of activity in palliative medicine: calming pain symptoms, psychosocial support to patients and their caregivers and ethical issues related to end of life.

The term “life-threatening or vestigial disease” encompasses a broad population of patients of different ages and different diagnoses, which adversely affect the patient's daily function or reduce his/her life expectancy. That is why palliative medicine/ care is intended for next population (4):

Children and adults who suffer from congenital diseases or conditions that lead to addiction on treatments that keep them alive and/or long-term care of their guardians to provide care in order to perform daily activities.

People of any age suffering from acute, severe and life-threatening diseases (such as serious injury, leukemia or stroke). When/ if healing occurs, it is a very time consuming and tedious journey filled with significant disabilities.

People who suffer from progressive chronic conditions (malignancy, chronic renal failure, liver disease, stroke that results in significant

functional impairment, severe heart or lung disease, frailty, neurodegenerative diseases and dementia).

People suffering from chronic and life limiting injuries due to accidents or other forms of serious injury.

Seriously and terminally ill patients (such as people suffering from dementia in the final phase of terminal stage of cancer or severe disability sustained due to a stroke), which are unlikely to recover or stabilize, and that intensive palliative care taking focus and goal of care during the time that they have left.

An interdisciplinary team cares for terminally ill and it consists of: a physician with training and experience in palliative care/ medicine, nurses trained in the domain of palliative care and effective management of pain and trained to care for terminal patients and the needs of the family/ the patient's caregiver, social worker with clinical and educational experience to meet the needs of counseling and working on the case of the terminally ill person, their families and/ or caregivers, chaplains and spiritual advisors with appropriate training, experience and skills in pastoral counseling and support in mourning, trained volunteers supervised by volunteer coordinator and counselor coordinator trained to assist in mourning (5).

Pain is the leading symptom in caring for the terminally ill. The official definition of pain of the International Association for the Study of Pain (IASP) (6), adopted by the World Health Organization, is that pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described at the time of such damages. Because it embraces the whole person, with significant physical, emotional, social and spiritual dimensions in the development, progress and treatment, the notion that the treatment of chronic pain requires a multidisciplinary approach had been in the modern world for decades. It is therefore not surprising that there are mandatory multidisciplinary centers for the treatment of pain in the world, and that training in pain medicine independent sub specialization and that a clinic for the pain is a component of palliative medicine. In everyday clinical practice with the terminally ill there is a significant correlation between pain and psychiatric disorders, so the pain of a possible symptom in most, if not all terminally ill, and the large number of patients with chronic pain has some of the associated diagnosis. This connection is not present only in the terminal stages of the disease and in the elderly population. Her presence exist inside all ages, from childhood to old age, gathered that each of these periods have their own specifics. Contemporary literature and clinical practice increasingly point to the connection between chronic pain and depression, how at a neurobiological, so at a clinical level.

Pain is defined as normal, predictable physiological response to chemical, temperature or mechanical stimuli, caused by surgical procedure, injury or acute illness. This is the initial phase of strong durable nociceptive individually modulated cascade, which in a very short period of time by neural sensitization and by

remodeling suddenly turns into chronic pain. In palliative medicine symptoms of pain are treated regardless of etiology. In patients with cancer, pain is most severe symptom with prevalence from 20–50% in the early stages of the disease and 75% of patients have moderate to impending severe pain (7).

Regarding the terminally ill, it almost always considers chronic pain. In chronic pain, the nervous system homeostasis is being changed which leads to adaptive neuroplastic changes within the nervous system with the possible collapse of the physiological mechanisms of negative feedback. It develops gradually, lasts for days, months and even years. Most often it is a dull ache, it is difficult to determine where it comes from and it expands to environment (8). Its treatment is more severe and lasts longer than the treatment of acute pain. It leads to significant changes in personality, in functioning and in the way of life as well as making many life decisions that are often of ethical issue.

Freeing the patient from pain and getting rid of pain syndrome in all its multidimensionality directs the palliative care to quality of life. Quality of life can be determined only by every palliative patient individually. The recommended procedure to resolve symptoms should be discussed with the patient and family members at any time, and if at all possible they should meet the patient's wishes, and thus achieve the ethical principles of autonomy and justice.

Medical science associated with the advancement of technology greatly contributed to improving the maintenance of human health, and therefore inevitable to prolonging human life and at the same time this act has developed some new problems related to the issues of death and dying. With such a growing use of various medical-technological aids in order to prolong the length of life, medicine necessarily had to develop and has developed a new set of principles to aid in solving complex medical and ethical issues.

Coordinated program of palliative and supportive care responds to the needs of dying patients insuring alternative to aggressive, curative-oriented care. Palliative care does not justify, nor participates in any process that aims to speed up or prolong the patient's death. On the contrary, all aspects of care are focused on creating comfort, respect for life and optimizing patient's control and autonomy (9). The patient and his family should be involved in decisions related to the treatment and care of the patient in a way that they provide enough information about the disease, treatment, access and the ability to be able to realize the informed consent, the doctrine of medical ethics.

Ethics of palliative medicine is achieved through the ethical values of the four fundamental ethical principles.

The first two principles were defined by Hippocrates 2500 years ago as a beneficence and nonmaleficence: these are the principles that from the person caring for the patient require liability of maximum benefit and minimum harm to the patient. Fulfillment of these

principles may, perhaps, appear as a very simple task, however, what may be a culmination of a patient's well-being and safety, does not have to be for another patient or it doesn't seem that it has reached its maximum of charity and minimum harm. The vast diversity of cultures, religions, beliefs and ways of life suggest that the caregivers need not hesitate to ask the patient what is best for him and how to do it best.

It is with this type of communication we as caregivers provide maximum of doing well, that is not doing the harmful.

Somewhat newer principles defined by Beauchamp and Childress (1989) are autonomy and justice. Autonomy is, as a principle, based on the patient's self-awareness and self-determination and their right to decide. The concept of integrity (integration) and informed consent is the key to any debate on the autonomy of the patient. Also, we as caregivers, members of the interdisciplinary team (any doctors, nurses or any other health care professionals) need to be prepared for "an informed disagreement-rejection" as one of the possibilities of the patient's selection and thereby prove our ethical maturity towards respect of the patient's autonomous decision-making.

Equity represents a main principle in solving all the discussion of which is the core problem in diversity. Diversity (inequality), especially of opinions and views, is the most common problem of the patient's disbelief in the decisions of professional medical personnel and interdisciplinary team.

Truthfulness and trust should be mentioned as derived ethical principles whose role in palliative care is actually foundation for building a good relationship between the patient and members of the interdisciplinary team, and finds its stronghold in telling the truth, keeping secrets and fulfilling promises.

Ethics of palliative medicine related to attention and focus towards terminal patients was determined through five principles: the principle of truthfulness, the principle of therapeutic proportionality, the principle of double effect, the principle of prevention and the principle of not leaving and treatment of pain (10).

The principle of truth is based on truthfulness as the foundation of trust in interpersonal relations. To tell the truth the patient and his family represents an advantage for both (the principle of charity) because it allows patient's active participation in the decision making process (autonomy). In medical practice, there often occur situations where telling the truth is not a simple medical task: giving a bad news such as a diagnosis of progressive and incurable disease, or a prediction of an impending and inevitable death. Falsely paternalistic attitude often occurs in these circumstances where the truth is concealed from the patient. This act results in entering into a vicious circle called the "conspiracy of silence" that can, in addition to imposing new forms of suffering on the patient, cause serious injustice (11).

At the same time, in the process of conveying the truth, regardless of its severity, one should be careful in what, how, when, how and whom to inform. This act requires professional thoughtfulness and teaching to help patients in a faster understanding and acceptance of their situation. Falsehood and vanity are common opponents to a quality physician-patient relation or caregiver-patient relation that insulate patients from behind the wall of words or silence, and prevent them from accepting the therapeutic benefits of the division of fear, anxiety, and other obsession. It is impossible to implement palliative medicine / care without the prior obligation of openness and honesty for the truthfulness of the facts (12).

The principle of therapeutic proportionality is based on the moral obligation to fairly implement all therapeutic measures that are in relation of proportionality between the applicable funds and predictable results. There are elements that necessarily have to be taken into account; the utility or futility of measures, alternative acts, risks and benefits of therapy as well as its price. Doctors have a dual responsibility: to save lives and alleviate suffering. It is without a doubt that alleviation of suffering at the end of life gets more and more attention. Decision to maintain life when it is essentially useless is a part of medical skills. The doctor is not required to maintain life "at all costs" (13). Focus priorities change when a patient is apparently dying and there is no obligation of how to apply treatments that prolong life.

The principle of double effect: severe pain, difficulty breathing, anxiety, agitation, and mental disorientation are often present in terminal patients. In order to control these symptoms the use of various pharmacologic agents is required. The use of morphine, among other things, can cause respiratory depression, while other preparations reduce the level of alertness or even deprive a patient of consciousness. There are fears that the negative effects of these medical interventions may imply a form of euthanasia. With this trepidation, it is important to recall the traditional ethical principle of double effect. That connotes the conditions that must be respected in order to justifiably carry out an act of double effect – one good and the second bad (14).

The principle of prevention: predicting the risk of possible complications and/ or symptoms that occur with the highest frequency in the development of certain clinical condition is a part of the medical liability. Implementation of the necessary measures in order to prevent such complications and consequently advising families on the best procedures that need to be followed allows avoiding unnecessary suffering of the patients, and thus their families (15).

Principle of not leaving and treatment of pain: the principle of not leaving refers to the ethical/ moral obligation of the doctor not to leave the patient in the event of his (the patient's) decision regarding refusing treatment ordained by his doctor even if the doctor would consider that the refusal is inappropriate (16). Situated beside his

patient and establishing a form of empathic communication, the doctor may achieve the patient's rethinking of a certain decisions regarding his health and treatment.

In the implementation of palliative medicine/ care about respect for the patient's decision today there are a number of documents two of which are necessary in the context of palliative medicine for everyday work with the terminally ill and their families. It regards informed consent and biological testament (living will, biocard) map of self-determination.

Informed consent is a patient's statement that empowers physicians to implement certain measures – therapy (17). Biological testament represents a document by which a fully aware person expresses his own will of procedures with which he wants or does not want to be exposed in the event of serious illness or sudden trauma, if he is not able to express their own will (18). The importance of biological testament is extremely important in palliative medicine and it is reflected in the fact that the basis of the composite and testament signed palliative care team will know exactly how to respect and act in accordance with the wishes of terminal patient, especially if the patient is in a state in which decisions are not possible to make on his own. Also, another problem arises when family members have opposing views in the care and treatment of the implementation of its terminal patient, or if you do not respect the wishes of his family members. Then the biological testament is held as a final decision or, better yet, a guideline.

Advance directives are specific instructions, prepared in advance of serious illness, that are intended to direct the medical care for specific individuals if they become unable to express their health care choice at a future date (19). This allows patients to participate in making their own decisions regarding the care they would prefer to receive if they contract a terminal illness. There are several different types of advance directives in use today in the world: living will, verbal advance directive, durable (or special) medical power of attorney

Living will is a legal document, written and signed by an individual in the presence of witnesses, that conveys the instructions of that individual regarding health care interventions, desired or not desired, in the event of terminal or irreversible illness and when the person is incapable of verbally communicating wishes regarding health care (20). This document shouldn't be confused with a last will and testament, the purpose of which is to distribute assets after a person's death. Interventions addressed by living wills: cardiopulmonary resuscitation, nutritional support by other than oral means, hydration by other than oral means, antibiotics, transfusion of blood products, invasive procedures and diagnostic studies including, but not limited to, blood tests, spinal taps, and x-rays and scans, desire to be hospitalized or remain at home.

Verbal Advanced Directives

Many individuals have, in the course of conversation with loved ones, expressed their desires concerning care near the end of life, but did not have the foresight to execute a written advance directive prior to becoming unable to make a health care decision. Alternatively, for psychological reasons, some individuals just can't bring themselves to sign a document that addresses issues revolving around the end of life. For these people, the documentation of their verbal instructions by their physician and/or health care provider (hospice) may be sufficient to constitute a legitimate advance directive.

I durable (or special) medical power of attorney is a legal document that allows an individual to appoint a responsible person (usually called a health care surrogate or proxy) who is empowered to make health care decisions in the event the individual becomes unable to make and communicate such decisions personally (21). This document provides for power to make medically related decisions only, and does not give that individual the authority to make legal or financial decisions. Although health care proxies are usually family members, any individuals such as a close friend, clergy member, or even physician – may with the individual's permission be designed for this role.

CONCLUSION

Palliative medicine/care aims to relieve suffering and improve quality of life for patients with advanced illness and their families. It is provided by an interdisciplinary team and offered in conjunction with all other appropriate forms of medical treatment.

Medical ethics and palliative medicine/care are nowadays entering into a new and fascinating phase of interaction and cooperation. On the one hand, many moral issues and dilemmas arise in the practice of palliative care. Palliative care according to Hare and Clark has value in itself. It is important that future healthcare is well adapted to the changing needs of patients. Good care will at least be as important as high-technology, cure-orientated medical intervention. Also, the search for a good death is likely to permeate future societies as people seek to avoid suffering and a loss of dignity (22). Further attention to palliative care modalities can be one of the answers to requests for euthanasia, although it does not imply that palliative care needs to be developed first and foremost in order to provide an antidote for euthanasia. The major goal of palliative care is to provide good care and to improve the quality of life of the patients and their families, not to avoid euthanasia. This may be a secondary goal, ethically imperative, but the first internal goal of palliative medicine and palliative care practice is to care for those who are about to lose human existence (23).

REFERENCES

1. BRKLJAČIĆ M 2009 Bioetički, zakonodavni i organizacijski preduvjeti primjene suvremenih trendova u hospicijskom pokretu u zdravstveni sustav Republike Hrvatske. Medicinski fakultet Sveučilišta u Rijeci. Doktorska disertacija, p 7–8
2. PREPORUKA REC 2003 24 2004 Povjerenstva Vijeća Europe državama članicama o organizaciji palijativne skrbi. Zagreb: Hrvatsko društvo za hospicij/palijativnu skrb, HLZ 5–7
3. DOYLE D, HANKS G W C, MAC DONALD N 1998 Oxford textbook of palliative medicine. Oxford University Press, Oxford, New York, Tokyo, p 18
4. BRKLJAČIĆ ŽAGROVIĆ M 2010 Palijativna medicina – spoj stručne humane skrbi za terminalno oboljele i medicinske etike. *Acta Med Croat* 64: 235–310
5. CUMMINGS I 1998 The interdisciplinary team. In: Doyle D, Hanks G W S (ed) Oxford Textbook of Palliative Medicine. Oxford University Press, p 19–30
6. ŠAKIĆ K 2009 Introduction of the perioperative pain. *Period biol* 111: 153–154
7. HASSENBUSCH S J, STANTON-HICKS M, COVINGTON E C WALSH J G, GUTHREY 1995 Long-term intraspinal infusions of opioids in the treatment of neuropathic pain. *J Pain Sympt Manag* 7: 527–43
8. MELDRUM M 2005 The ladder and the clock: cancer pain and public policy at the end of the twentieth century. *J Pain Sympt Manag* 29 (1): 41–54
9. KINZBRUNNER B M, WEINREB N J, POLICZER J S 2002. 20 Common Problems in End-of-Life Care. The McGraw – Hill Companies, USA, 2002, p 12–15
10. WORTHINGTON R 2005 Ethics and Palliative Care. Radcliffe Publishing, Oxford, p 27
11. WOODS S 2002 Respect for autonomy and palliative care. In: Ten Have H, Clark D (ed). The ethics of palliative care. Open University press, Buckingham, p 145–66
12. SCHOTSMANS P 2002 Palliative care: a relational approach. In: Ten Have H, Clark D (ed). The ethics of palliative care. Open University press, Buckingham, p 126–30
13. CONNOR S R 1997 So What is Hospice, Anyway? In: Connor S R (ed) Practice, Pitfalls and Promise. Taylor & Francis, Washington, DC, p 4–7
14. PESSINI L 2001 The principle of double effect. In: Pessini L (ed) Distanásia: Até quando prolongar a vida? Editora do Centro Universitário São Camilo. Edições Loyola, São Paulo, p 193
15. PESSINI L 2001 The principle of prevention. In: Pessini L (ed) Distanásia: Até quando prolongar a vida? Editora do Centro Universitário São Camilo. Edições Loyola, São Paulo, p 195
16. HIGGINSON I J 2006 End of Life Care. *J Palliat Med* 8 (1): 161–173
17. ŠEGOTA I 1999 Informed consent. Bioetički svesci 20. Medicinski fakultet Sveučilišta u Rijeci. Katedra za društvene znanosti, Rijeka, p 40–42
18. RUNZHEIMER J 2011 Ten ethical issue to address with your patients. In: Runzheimer J, Johnson Larsen L (ed). Medical ethics. Wiley publishing, New York, p 333–41
19. WEINREB N J 2002 Advance directives. In: Kinzbrunner B M, Weinreb N J, Policzer J S (ed). 20 Common Problems in End-of-Life Care. The McGraw – Hill Companies, USA, p 184–7
20. RUNZHEIMER J 2011 Ten ethical issue to address with your patients. In: Runzheimer J, Johnson Larsen L (ed) Medical ethics. Wiley publishing, New York, p 339
21. BOZEMAN M 2002 Ethical Issue: Medical power of attorney. In: Kinzbrunner B M, Weinreb N J, Policzer J S (ed). 20 Common Problems in End-of-Life Care. The McGraw – Hill Companies, USA, p 187–9
22. TEN HAVE H, CLARK D 2002 Conclusion: ethics and palliative care. In: Ten Have H, Clark D (ed). The ethics of palliative care. Open University press, Buckingham, p 233–50
23. TEN HAVE H, CLARK D 2002. Introduction: the work of the Pallium project. In: Ten Have H, Clark D (ed). The ethics of palliative care. Open University press, Buckingham, p 10