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ETHICAL ASPECTS OF THE NON-RESUSCITATION DISCUSSION WITH THE PATIENT AND ITS FAMILY IN PALLIATIVE CARE

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Abstract

The role of palliative care is to ensure the highest quality of life for the terminally-ill patients and their families. It is vital to integrate and develop palliative care programs within the structure of the community healthcare network under the conditions of demographic dynamics and due to the increase in mortality from oncological or non-oncological conditions. The patient's right to health is based on his/her state of well-being or health care that is judged by professionals with the right expertise. The principles of medical ethics, the limits of medical science, and the religious beliefs of medical staff, patients and their families, influence the individual decision of cardiopulmonary resuscitation.

Keywords: palliative care, quality of life, non-resuscitation, death.

Introduction

End-of-life care and medical care have been and continue to be at the center of ethical debates around the world (Breslin et al., 2005). The ability of modern medicine to treat, heal and prolong life is so advanced that it seems inconceivable an end without the intervention of resuscitation and resuscitation maneuvers, regardless of the damage they may cause. However, there are limits imposed by promoting the best interests of the patient and by respecting his/her dignity (DH-BIO, 2014).

Cardiopulmonary resuscitation in palliative care

Approaching the subject of death is one of the most difficult communication tasks for the physician. Effective communication in palliative care should address the meaning of threatening death for the patient and the patient support network, the associated losses, any regrets and anxieties that may occur later. Death is regarded by the patient as a defeat, by the attending physician as a failure, by the family as an event with important emotional consequences, and by society as a reduction of economic costs (Datcu & Petriş, 1997; Poantă, 2010). There are differences in availability and ability of patients to talk about their own imminent death. In addition, various cultures have different ways of approaching the subject of death (Block, 2001).

Cardiopulmonary resuscitation is an emergency procedure for reviving heart and lung function, involving special physical techniques and often the use of electrical and mechanical equipment (DH-BIO, 2014).

The purpose of the resuscitation procedure is the same as for other medical interventions: to maintain life, to suppress the suffering, to reduce the neurological deficit, to improve the state of health.

The principles of medical ethics, the limits of medical science, the cultural, philosophical and religious beliefs of the medical staff, patients and their families influence the individual decision of cardiopulmonary resuscitation.

Respect and empathy for patients should be the basic rules of the medical profession. Most patients want to be treated as equal partners in the discussion with the doctor (Curtis & Burt, 2007).

The physician's rights and duties cannot be viewed and exercised in the abstract, but only in close connection with those of the patient. It is the patient who ultimately suffers the consequences of applying or not applying a particular therapy or intervention. Cardiopulmonary resuscitation can produce a cure without sequelae, but it frequently results in a series of problems, such as uncertainty and anxiety caused by approaching death, caring for the patient who is suffering. If a patient is legally fit and has a normal state of consciousness, he or she can express his/her will regarding treatment and care.

Patients' families often wonder if refusing cardio-pulmonary resuscitation means „killing” the patient. The purpose of refusing a therapy is to avoid adverse consequences for the patient and not to end his/her life. If the patient wishes to die without the treatment in question, then it is considered that his/her death was due to the underlying disease. When a patient is undergoing treatment, the doctor together with him/her will set a clear target. As with the refusal of a therapy, the reason for its withdrawal should be the avoidance of adverse consequences and not inducing the patient's death. While death is the anticipated result of withdrawal from therapy, therapeutic „fierceness” in certain situations would be futile.

Principles of medical ethics and decision regarding CPR

There are four fundamental principles of medical ethics: autonomy, benevolence, non-maleficence and justice. In accordance with the principle of autonomy, it is the patient's right to decide what treatment he/she is accepting and which he/she is refusing. Medical professionals are required to provide honest and complete information (Doyle & Woodruff, 2008).

From the ethical and moral point of view, the patient decides whether or not he/she wants to know the diagnosis, how much he/she wants to know and at the same time whether this information should also be communicated to family members. Whatever is done or said must be for the benefit of the patient. As long as they are advised, people generally decide for their best interests. If the patient wishes to discuss the issue of resuscitation or non-resuscitation, this should be observed. For each intervention, the potential benefits must be carefully weighed against potential adverse effects. Regular dialogue to agree on the goals of care will help the patient, family, and care team to have a better control and clarity about therapeutic options. The goals are dynamic, will evolve and will be refined as the disease evolves.

Respecting the patient's autonomy is also reflected in the medical decision taken in advance- the so-called „advance directive“. Advance directive is formulated in written by a competent person and indicates his/her wishes regarding his/her medical treatment or the designation of a surrogate person to take these decisions. Advance directive is to be applied when the person becomes incompetent and cannot decide for him/herself anymore. It can be of two types: accepted medical care („living will“) – a written document that stipulates the type of treatment or procedures for prolonging life if the patient reaches the terminal stage of a disease and the designation of a surrogate persons, usually a relative or close friend, who must make decisions on behalf of the patient based on his/her previously expressed preferences. If the patient has not expressed such preferences, the surrogate should decide based on the best interests of the patient. The patient can also decide if he/she wants to be informed with other information that could cause suffering. With his/her consent, relatives and friends can be informed about the evolution of investigations, diagnosis and treatment (General Medical Council, 2009).

Even in the case of a proper communication between the patient or his/her family members and the medical team, decisions regarding *life support therapies* can be problematic because they involve important ethical conflicts between autonomy and charity, autonomy and the principle of „*not doing harm*“, *non-abandonment*, *pronouncement and benefit and*

allocation of resources by society. The conflict between autonomy and beneficence is the basis of the dilemmas involved in life support therapies (Teres, 1992; Ruark & Raffin, 1988).

Allowing the patient's death by refraining from resuscitating or giving up supportive therapy violates the principle of beneficence and their insistent continuation that of autonomy. Because preserving life is in the patient's legitimate interest, giving up life-prolonging therapies can create an ethical conflict. However, the ethical and legal limits of the patient's autonomy have not yet been clearly defined (Teres, 1992; Ruark & Raffin, 1988).

The decisions regarding healthcare are also based on the principle of futility, related to the duration of life and the quality of life. It is considered futile the treatment that will surely fail or the treatment that simply prolongs the process of death. In patients with advanced progressive chronic disease, cardiorespiratory resuscitation is unlikely to be successful. Cardiopulmonary resuscitation is inadequate if the chances of survival are zero or if the patient is expected to survive, but without regaining his/her consciousness (Fritsche & Girardot, 1992).

Fidelity or non-abandonment is an important ethical principle being described as the „essence“ of the medical ethics. The doctor is obliged to make the patient or the „surrogate“ understand his point of view; if he fails and feels that morally he cannot continue to carry out the patient's therapeutic plan then it is imperative to find a another doctor to continue it (Fritsche & Girardot, 1992).

Non-resuscitation of the terminal patient

„Do not resuscitate“ (DNR) refers to the expression of the right of a competent adult or of the legal representative of an incompetent patient to refuse cardiopulmonary resuscitation, the decision being based on the information provided by the treating physician.

The term „do not attempt resuscitation“ (DNAR) indicates more precisely that resuscitation may fail. Particular attention should be paid to informing the patient about the DNAR decision. If a second opinion is required, this request must be honoured, whenever possible. It has been stated that „therapeutic fierceness“ in certain situations is unnecessary, costly and often involves only the doctor's vanity (Teres, 1992).

Decisions regarding DNAR are sensitive and complex and need to be taken by experienced members of the healthcare team and must be recorded carefully. Advice should be sought if there are uncertainties.

Another aspect is the costs of the medical care provided to terminally- ill patients, which represent a significant part of the total costs of the medical care. The physician's task is difficult when the patient is critically ill. Apart from the individual ethics, the so-called collective ethics reminds that there is a limited amount of medical resources. However, general ethical principles and especially the importance of ensuring the best interests of the patient must be kept in mind (Ruark & Raffin, 1988).

The absence of clear legislative rules, the aggressiveness of the family, the fear of the doctors of not being sanctioned, can cause the medical teams to initiate unnecessary cardiorespiratory resuscitation (Ruark & Raffin, 1988).

The Romanian Law offers the patients the possibility to formulate advance indications concerning their healthcare. Thus, the patient, properly informed, may request that resuscitation not be started in the case of cardiorespiratory failure. In the daily practice, there is a marked reluctance of the patients' families to express in writing the agreement not to initiate medical interventions (Fritsche & Girardot, 1992). There are cases in which the family of a patient whose resuscitation would be considered unnecessary by the medical staff asks to do everything possible for the loved one even if adverse effects and risks far outweigh the benefits. The current legislative context in our country does not provide for the ethical

obligation to discuss with patients about resuscitation maneuvers (Bremer & Sandman, 2011).

The role of communication in palliative care and in decision – making regarding CPR

The talent of a good communicator consists in conducting a conversation in which the patient and/or his/her family understand the information and gradually create their own perspective on the future. For effective and quality interaction, the physician must have interpersonal and relational skills. Interpersonal skills consist of: the ability to structure the dialogue and the ability to provide easily understandable information. Communication is facilitated by both verbal and non-verbal aspects. Patients and their families should be guided to a deeper awareness of the medical situation in a framework adapted to their cognitive and emotional status (Webb-Peploe, 2001).

At the same time, it is important to ignore the values of the medical team and to help the patient and the family to create their own opinion about what is best for the patient in relation to his/her medical condition. It is important for the medical professionals to keep in mind that in the process of communication with the patients, his/her trust in the medical team is essential (Mularski et al., 2005).

Transparency must be demonstrated in the presentation of the arguments in favor of approaching the topic of non-resuscitation and time should be devoted to discussing the pros and cons and also the most unfavorable scenario. The doctor should also try to find out the patient's perception of the disease and his/her own values related to medical care values. These are questions that lead the patient to a discussion about values. Questions may include: „What causes you concern?“ and „What is the most important thing for you if your time is limited?“. It is important that medical staff be prepared for the patient's emotions such as fear, pain and sadness. (Doyle & Woodruff, 2008).

The emotional reactions of the patient are often unpredictable, making subsequent communication and care difficult. Dismissal without a word can make patients feel abandoned. By ignoring the end of the relationship, clinicians miss an important opportunity, because the gesture of saying goodbye can have a strong positive effect on both the patient and his/her family. By saying goodbye, the doctors acknowledge the end of the relationship and at the same time emphasize its importance, giving the patient the feeling that he is appreciated and cared for, not abandoned (Block, 2001).

In the event of a conflict (as is often the case, due to poor communication by both parties, due to lack of understanding, medical culture or media-induced biases), when the family insists on continuing unnecessary, meaningless therapy („to be doing everything possible“), then the medical team can opt for its continuation for a predetermined period, and also to discuss/re-analyze the situation with the family (Larcan, 1992). In case of persistence of divergent opinions between doctor and patient/family, the literature recommends requesting another medical opinion, transferring the patient to another medical service or the case be referred to an ethics committee (Sgreccia, 2007). Also, for the prevention of conflicts, clinical protocols have been proposed regarding the communication with the families of the patients in the terminal state, protocols for addressing the emotional and informational needs of these families, strategies for minimizing conflicts and establishing the limits of some treatments or guides for doctors who are in dispute over the uselessness of end-of-life treatments with the patients' families. The advance directives mentioned by the patients could resolve some of the disputes that may arise at the end of their life (Sgreccia, 2007).

It is necessary to consult the Ethics Committee in the following situations: a patient without discernment and without the desire to live that transfers the decision to his/her family or whose family does not accept such a situation; when a family presents a solution that differs from the one adopted by the patient in his/her initial decision; in case of unclear

cognitive status following psychiatric consultation. The doctor should never use the phrase „nothing can be done“ anymore. Basically, something can always be done to improve the patient's condition (Biserica Ortodoxă Română, 2012).

The spiritual approach to terminally-ill patients

It is important to emphasize the need for palliative care when the patient has a chronic progressive disease. The dying patient also needs spiritual support. Accompanying a patient to death in a human and professional way, means to respect his/her dignity and to recognize the beauty of life until its end (Webb-Peploe, 2001).

From a Christian perspective, medicine is considered a healing art, which encourages the approach of the patient and his family to alleviate suffering. The physician must show compassion to the patient during the dying process. The fear of abandonment is an aspect of death that can be fought and defeated. For Christians, death is a natural process, and the moment of death is decided by the deity. Therefore, we do not have to do everything in our power to delay God's decision. We should not be ungrateful for everything He has given us - including our bodies – but we should not fear death.

Each death experience is unique, individualized, and may affect the behavior of the medical care staff. The Christian religion rejects the theory of soul destruction with death. The soul ensures our spiritual immortality, after the physical, biological death of the body. Another help that the Christian faith offers to those who are about to leave one's life is how our fear of death is explained, an almost general feeling and how we can overcome or diminish that feeling. The best answer is to explain in simple terms the meaning of each sign that appears (respiratory changes, skin changes, bradycardia, drowsiness, etc.), which can help and guide the family in deciding the time spent together with the patient and the desire to say goodbye to. An older man's tendency is to exacerbate the associated pathology, making communication sometimes difficult (Colegiul Medicilor din România, 2005).

Open, honest, balanced communication with the family is the key to reducing/eliminating a possible family-doctors conflict and also facilitates the easy transition to an atmosphere of calm, resignation, understanding of the state of end of life in conditions of comfort and peace of mind.

We cannot forget that man is an earthling. There are complex situations that should be managed according to a basic principle, that of valuing life and at the same time accepting natural death (Bernat, 2005).

The passage into the „eternal life“ of every human being is an inevitable event that can only be postponed for a finite time. The death of the human being must be a worthy one, in peace and comfort, without unnecessary grief, when all the assessments made dynamically show the uselessness of any medical intervention, no matter how sustained and well-intentioned it may be. The terminally ill patient must be assisted by the medical team with love and devotion. It is the moral duty of the physician to show compassion, understanding, towards the patient in the terminal stage and towards his/her family, giving them all the needed emotional support (Țurcanu, 2007; Perron, Morabia & Torrente, 2002; Verspieren, 1999).

Conclusions

It is necessary to develop guidelines on the indications of non-resuscitation in terminally-ill patients, which also include the rights and decisions of the patients.

The patient's right to health includes measures to protect physical and mental health and/or measures to prevent illness. The right to specialized medical care on the verge of death is one of the essential human rights.

The role of palliative care is to ensure the best quality of life for the patients and their families. It is necessary to integrate and develop palliative care programs in the structure of the community health care network under the conditions of demographic dynamics. Making a therapeutic decision must properly analyze the benefit-risk ratio and its impact on the quality of life.

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