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Selected aspects of end-of-life care in the Intensive Therapy Unit

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ABSTRACT

End-of-life (EOL) care represents a significant component of palliative/hospice care. It is applied in terminal hours, days or weeks of life, which require a very scrupulous, professional protection and palliative treatment, targeted at alleviation of sufferings. Mortality in wards of anaesthesiology and intense therapy (ICU) reaches 17%-24% and frequently, despite application of modern therapeutic methods, the patient dies.

This paper aims at drawing readers' attention to selected aspects of care given to patients and their families in the end-of-life in ICU. Dying represents a very difficult process not only for the patient and his/her family but also for the staff taking care over the patient. It represents a dynamic process and, therefore, the management should be modified depending on altering condition of a patient and his/her relatives; it is linked to adaptation of care and symptomatic treatment and to meeting half-way anxieties of patient's relatives. The patient should be viewed in his/her entire set of biological, psychic, spiritual and social needs and it should be born in mind that securing an appropriate comfort of terminal moments in life is occasionally more important than a heroic battle for every minute of life. In the terminal period of life quality of life depends on an appropriate communication, acceptance that the patient and his/her family keep the key for undertaking decisions, for a continuous care, emotional support, for assurance of an appropriate care, correct symptomatic treatment, spiritual, emotional and organizational support.

Keywords: end-of-life, care in terminal period of life, communication, LPC, DNAR.

Introduction

End-of-life (EOL) patient care and preservation of human dignity in a disease and death is particularly valid in wards of anaesthesiology and intense therapy (ICU). Mortality in such wards reaches 17%-24% [1-3]. The care in ICU frequently oscillates around palliative care. The palliative/hospice care (PHC) represent unequivocal terms. World Health Organization (WHO) accepted the following definition of palliative care: „Palliative care denotes such a care over ill patients and their close and dear which improves to maximum their quality of life by anticipation, prevention and treatment of suffering. Throughout the entire disease palliative care involves satisfying physical, intellectual, social and spiritual needs and support of independence of the patient, securing access to information and sat-

isfaction of patient's choices" [4, 5]. End-of-life care is not identical to PHC but it represents its significant component; it finds application in care of a patient who is close to death (i.e. in terminal days or weeks of life), but who remains still alive and who requires a very careful, professional care and palliative treatment, targeted at providing relief from suffering [4]. It happens that a patient is admitted to the ward in a situation when cause of his/her condition remains irreversible, e.g. in cases of patients at the terminal stage of an irreversible disease which inevitably leads to death and the patient dies, despite application of modern ways of treatment. The restricted potential for cure places the staff in a situation, in which apart from challenges linked to therapeutic activities ethical dilemmas appear, stemming from the necessity to con-

sider stopping invasive methods of treatment and to diagnose terminal period of life. The situation in which such a diagnosis begins to be considered induces stress and anxiety both in the medical staff and in patient's family [7]. Due to his/her condition and due to applied invasive technologies, e.g. intubation or mechanical ventilation, the patient him/herself has no chances to undertake the decision self-standingly. In view of the specificity of the ICU one of the most challenging in diagnosing EOL in the uncertainty related to choice of most appropriate moment for informing patient's family on the unfavourable diagnosis [8–10]. Both nurses and physicians express apprehension of stripping off patient family's hopes by informing them on the diagnosis. Studies indicate that medical staff, including nurses, are not adequately trained in this respect [11, 12]. Moreover, the care provided in ICU in end-of-life frequently complicates the short time of passing away. Most of deaths in ICU occur within 4 h after diagnosis of EOL [13]. The risk of a sudden death does not allow „to prepare the patient for death”, which is possible in cases of palliative patients. The nurses are confronted with an enormous challenge to provide an appropriate care to the dying patient and to his/her family [14]. With increasing frequency the need is stressed to assure the highest quality care to critically ill patients. In the care of patients quality of last moments in life is regarded more important than a heroic struggle for life prolongation [15].

Care of patient and of his/her family in the terminal period of life

Passing away represents a difficult period not only for a patient and his/her family but also for the staff taking care of the patient, it passes dynamically and the management should be modified, reflecting the changing and surprisingly variable condition of a patient and his/her close and dear. This requires that the care and symptomatic treatment are being appropriately adjusted and efforts are made to foresee apprehensions of patient's relatives [5].

In securing an effective continuity in care of patients in EOL, application of recommendations formulated in Liverpool Care Pathway (LCP) can be helpful. In their primary version, the recommendations were formulated at the end of 1990s, aimed to improve care of patients at EOL. They were worked out by employees of a hospice in Liverpool together with physicians of Royal Liverpool and Borden University Hospi-

tals, originally for needs of oncological patients. LCP assumes that a physician and nurses in common have to admit that there are no chances for improvement of health condition in a severely ill patient. Consequently, in such patients administration of drugs prescribed for a given disease and invasive treatment are discontinued. The situation should be discussed with family of the patient and, if possible, with the patient him/herself. Condition of the patient should be evaluated every four hours. If improvement is noted by the medical staff, the traditional treatment should be reinstalled.

The determination if the patient is just about to die is important not only due to the potential to introduce an appropriate treatment but also because it provides the potential to inform the patient (if he/she wishes so) on advancement of the disease, so that he/she, being aware of the approaching death, will be able to choose an appropriate treatment in the terminal stage of life. LCP in ICU aims at improving care of patients in their terminal hours/days of life, by definition of clear aims of care on the basis of patient's bio-psycho-social condition [16]. For an appropriate functioning of the programme implementation of appropriate training is indispensable, as well as introduction of LCP pathway in individual wards [17]. Unfortunately in cases of patients in ICU the EOL takes a very short period of life and it is not always possible to introduce its appropriate management [18].

In 2003, Clark et al. presented the concept of seven key factors which affect quality of care over patients in EOL. They included communication, recognition of the patient and his/her family as most important in undertaking decisions, continuity of care, emotional support, provision of an appropriate care, an appropriate symptomatic treatment, spiritual support, emotional and organizational support [19].

In the care of patients in EOL an important ability is observation of the patient in the entirety of his/her biological-psycho-spiritual-social needs. Due to an inquisitive observation we can detect alterations and needs of the patient, with whom we frequently are unable to communicate verbally.

Communication with a dying patient represents an important art., in which a nurse plays a key role [20]. Laurette et al. suggest that an appropriate communication in ICU forms a groundwork of care in patients at EOL [4]. Most of the patients cannot properly communicate with either family or medical staff due to their health condition. We can hardly understand the language of dying persons and guessing the significance of the very restricted non-verbal transfer of informa-

tion (grimaces, groans, cry, repeated movements of an extremity, signs given by movements of the head, lips, eyeballs, blinking), even if difficult in interpretation, represent an important, undervalued system of communication [5]. The extraverbal communication provides base for nursing practice [20].

With approaching death of a patient much more attention should be devoted to support of his/her close and dear, who take care of the patient. In the care of the patient in ICU and of his/her family it should be kept in mind to appropriately transfer information and to be aware that the family may hear divergent data and communicates, both formal and informal ones related to health condition of the patient from several members of the therapeutic team. Due to extensive caretakers changes (work in relays) it may happen that the family receives erroneous communiques [21]. Studies demonstrated that family members of critically ill patients manifest high level of anxiety and fear, resulting from an insufficient communication with medical staff and lack of space (accommodation for the family) [22]. The level of fear is elevated also by the patient's surrounding itself (medical equipment, numerous leads, sound signals, alarms coupled to the medical equipment). Bach et al. point to a significant role of a nurse in providing emotional support to the family, resulting just from staying by the patient's bed or from conversation with family members [23].

It is common that patients in EOL suffer from pain [24]. It is frequently linked to execution of nursing procedures, such as change in position, aspirations or change of dressing. Pain alleviation in patients in EOL in ICU may be very difficult due to the applied sedation, which impedes evaluation of the pain. In cases of patients under sedation it is recommended to evaluate pain according to Behavioural Pain Scale and Critical-Care Pain Observation Tool [25, 26]. The alleviation of pain involves administration of opioids and anxiety-relieving drugs. In cases of using sedative drugs in patients in TPL frequently the principle of double effect in mentioned: administration of the drugs favourably alleviates suffering but unfavourably strips the patient of his/her awareness and the potential for abbreviation of life. Intervention which induces serious, anticipated unfavourable effects, including death remains morally admissible if undertaken with the intention to help the patient and unfavourable action represented a condition for obtaining a favourable effect. An unfavourable proved to be use of the „terminal sedation” term, which appeared in publications related to use of sedation in EOL. Application of sedation should not be mistaken

with euthanasia. A deep, permanent sedation is used very seldom and it used to be indicated in irreversible and advanced disease with expected death within the approaching hours or days. Use of sedation in high doses frequently proves indispensable in last hours of patient's life, in order to prevent discomfort, to alleviate pain and asphyxia even in a situation when such actions are linked to an increased risk for abbreviation of patient's life. The use of sedation in EOL always should assure comfort to the patient [27]. In such situation no clinical need arises to increase body hydration; such activity might augment the risk of „premortal rattling”, pulmonary oedema and peripheral oedema.

If there exist no doubts that the patient will die within days (e.g., in a neoplastic disease with metastases) an increased body hydration may harm the patient due to an increased amount of exudate in bronchial tree, providing no additional survival benefit and extra alleviation in suffering. In patients following a widespread stroke, who are unable to swallow but will survive perhaps longer than a few days, renal insufficiency develops and a pronounced thirst, if they are not extra-intestinally administered with fluids. They have to be rehydrated even of such procedure is thought to be pointless. Studies indicate that therapy with fluids and alimentation not always make the patient comfortable [28].

In patients who die or begin to die frequently a troublesome anxiety or excitation develops. At this stage of a disease communication with the patient is reduced or impossible. The only practical manner of relieving the symptoms involves application of a certain stage of sedation but the decision on necessity of administration sedation-inducing drugs can be undertaken exclusively by the medical staff with an appropriate knowledge and experience [29].

Scientific data prove that an effective relief of symptoms in EOL frequently results in abbreviation of life [3]. Tokarz, in studies conducted in ICU in Poznań, found that in opinions of 98% studied medical staff the care for comfort in terminal moments of life is important and only 2% of the staff heroically fights for life prolongation by every minute [15].

Involvement of a nurse in undertaking decisions related to a patient in EOL

In the context of care over patients in EOL in ICU, discontinuation of intense treatment pertains to the till now conducted treatment and undertaking no subsequent therapeutic initiatives. In Poland this topic con-

tinues to represent a taboo, infrequently discussed but frequently erroneously associated with euthanasia.

However, it should be remembered that the treatment obligation does not extend to the phase of the dying patient while medical interventions which prolong agony represent an unethical activity, breaching patient's right to a dignified death. Artificial elongation of an agony needlessly increases patient's suffering, suffering of his/her close and dear and negatively affects the therapeutic team. In daily hospital discussions the lack of acceptance for resuscitation procedures, undertaken, e.g., in cases of agony in terminal neoplastic disease, is clearly articulated. In European recommendations of 2004 it was agreed that a superior aim of persons participating in decisions in TPL should involve patient's benefit. The recommendations indicate that nurses should play a significant role in activities of the therapeutic team [30]. In studies conducted by the European Federation of Critical Care Nurses (EfCCNa) in 2005, presented at the congress of anaesthesiology nurses it was demonstrated that 145/158 (91.85%) interviewed nurses were engaged in care of patients in EOL while 73.4% (n = 116) of them took share in undertaking decision on stopping persistent therapy [31]. 63.5% of the interviewed nurses initiated a discussion on diagnosing EOL in a patient. Most of the interviewed nurses (58.7%) expressed the opinion that involvement of nurses in diagnosing EOL is indispensable for an effective communication between a physician and patient's family [32]. The role of a nurse involves, first of all, provision of an emotional support for the family. Due to her/his frequent contact with close and dear of the patient, the nurse develops a confidence required in relations with families of dying patients. A professional, based on reciprocal respect cooperation between nurses and physicians promotes provision of support to the families. Studies conducted in USA indicated that an improper collaboration between nurses and physicians in care of a patient in EOL was linked to a more pronounced suffering of patient's family and lower professional satisfaction of nurses. Authors of the study stressed that accord between the two professional groups in diagnosing EOL is favourable for the dying patient and his family [33]. The final decision on discontinuation of persistent treatment remains the responsibility of physicians even if it is accepted that diagnosis of EOL should be based on condition of the patient, opinions of the family and medical staff and occasionally the consensus cannot be achieved [34–36]. It remains important that standards related to EOL are uniform [37–39].

In Poland undertaking the decision on implementation or abandoning resuscitation measures (DNAR – Do Not Attempt Resuscitation) represent still a taboo topic, reluctantly officially considered and, therefore, in awareness of several physicians erroneously associated with euthanasia. It occurs that saving measures are undertaken in situations forecasting no success and even when the patient provided no consent for starting such activities. In Polish hospitals decisions on abandoning resuscitation seldom are being documented [40]. The decision on not undertaking resuscitation in cases of circulatory or respiratory arrest is undertaken by physician who is in charge of the therapy. Before undertaking such a decision consultation with another physician is advisable, a physician who might help in an objective evaluation of the situation as well as an attempt to establish will of the patient related to undertaking resuscitation attempts. It would be advisable also to discuss the matter with the patient's relatives. In course of the conversation with the family it should be stressed that the final decision is undertaken by the physician and shifting the responsibility to patient's relatives makes no sense and is unjust. In Polish hospitals frequently patients are fully excluded in discussion related to his/her fate and role of his/her family becomes minimised. Such a practice breaches patient's right for autonomy and breaches the principle of expressing conscious consent for the manner and range of treatment, resulting from the paragraphs of the penal code, Act on Profession of a Physician and the Code of Medical Ethics [41, 42]. Role of the patient and his/her family in the process of establishing the range of therapy in critical conditions is radically different in individual countries. In USA autonomy of the patient represents a priority and, therefore, key decisions related to treatment, including management of critical conditions are undertaken with his/her involvement. In Europe, the range of medical management more frequently is discussed with the family (77%) than with the patient him/herself (26%) [34]. In Poland, the nurse taking care of the patient is not considered by interviewed physicians as a partner and a full standing member of the medical team. Therefore, nurses' opinion on selection of the manner of treatment in severely ill patient is not taken into account and, moreover, physicians see no reason to alter this type of practice [40]. Cause of the phenomenon seems to stem from work organization in hospitals. Staff deficiencies cause that every nurse cares for an excessive number of patients and, therefore, a nurse remains for every of the patient a foreign and anonymous person. Consequently, no premises exist to include the nurse to such a dif-

difficult discussion. On the other hand, in France nurse staff participates in 54% in decisions on reduction of therapy [44]. In Portugal, 35% physicians see the need for including nurses to the team deciding on resuscitation [44]. A similar opinion is expressed by 30% Australian physicians and 36% patients [45].

Support of medical staff in the course of its care over patients in EOL

Care of patients in EOL is associated with enormous stress to the nurse staff [46–48]. Its awareness of mastered capacities and satisfaction from professional work can become impaired, a sensation of a guilt, imperfection and failure may appear. This becomes evident particularly in younger members of the team. Lack of support in such situations may induce restraint of sadness and anxiety, resulting in a mounting stress [49]. In questionnaire studies conducted by Sleziona and Krzyżanowski among 120 nurses a decisive majority of participants argued that they experience problems in certain aspect of care involving dying patients and require a support (e.g. by the close and dear) to cope with surviving such problems [50]. This points to the need for an appropriate education and self-improvement in the range of psychology in order to recognize reactions of a patient and his/her family. This is also significant for more accurate recognition of own personality traits and development of ways of how to neutralize effects of exposure to difficult situations [51].

Such an event should be discussed with the team using techniques of constructive and positive criticism and the persons in need should be suggested to take advantage of psychologist's support. The way of discussing the matter should be carefully adjusted to the needs: this may involve an informal talk or professionally conducted psychological consultation. The grief following experiencing death at work may represent normal reaction to the non-standard situation. This occurs particularly frequently in a situation when we deal with death of a young, till now healthy person, who within few hours or days entered EOL, e.g., due to a rupture of cerebral aneurysm. According to several authors, there exists a real need for mourning following death of a patient [49].

Summary

Care of patients in EOL is linked to enormous stress for the staff taking care of the patient and his/her family. The moment of undertaking a decision on discontinua-

tion of an intense treatment or giving up resuscitation measures poses a problem and, therefore, it is important to unify standards related to EOL. Educational activities should be supported, which broaden knowledge on EOL since this will allow to assure the possibly highest quality care of patients in EOL and his/her family.

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