DYING WITH DIGNITY, A MISSING DEBATE IN ALBANIA

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Abstract

In our daily work as clinicians, we have all faced the moment when the patient no longer benefits from the therapy defined according to medical protocols and the patient's treatment plan must change from therapeutic to palliative or supportive. The medical progress of the chronically ill will inevitably lead to the patient's death. The way the patient and his family members will face death is directly related to the work of the physician and the medical staff and also to the explanation of the prognosis of the disease and the expectations from the therapy or medical equipment to help the therapy. As a function of this process, concepts (new or not) such as: actively dying, end of life care, terminal patient, which help in determining the stages of a chronic disease with an inevitable end, come to the aid of the physician and the staff. This text is not intended to serve as a guide, but aims to raise a debate that is missing in Albania regarding ethical, medical, practical aspects of the daily work of the clinician (internist) regarding patients in the terminal stage of the disease, the approach to death from both the doctor's point of view and that of the patient and his family members.

Keywords: actively dying, end of life care, terminal patient

TË VDESËSH ME DINJITET, NJË DEBAT I MUNGUAR NË SHQIPËRI

Abstrakt

Në punën e përditshme si mjekë klinicistë, të gjithë jemi përballur me çastin kur pacienti nuk përfiton më nga terapia e përcaktuar konform protokolleve mjekësore dhe plani i trajtimit të pacientit duhet të ndryshojë nga terapeutik në paliativ apo suportiv. Ecuria mjekësore e të sëmurëve kronikë, do shkojë në mënyrë të pashmangshme në drejtim të vdekjes së pacientit. Mënyra se si pacienti dhe familjarët e tij do të përballen me vdekjen, është e lidhur drejtpërdrejtë me punën e mjekut dhe stafit mjekësor dhe po ashtu me sqarimin e prognozës së sëmundjes dhe pritshmëritë nga terapia apo paisjet mjekësore në ndihmë të terapisë. Në funksion të këtij procesi vijnë në ndihmë të mjekut dhe stafit edhe koncepte (të reja ose jo) të tilla si: vdekje aktive, kujdesi në fund të jetës, pacient terminal, të cilat ndihmojnë në përcaktimin e stadeve të sëmundjes kronike me një përfundim të pashmangshëm. Ky material nuk ka për qëllim të shërbejë si udhërrëfyes, por synon të ngrejë një debat të munguar në Shqipëri, në lidhje me aspekte etike, mjekësore, praktike, të punës së përditshme të mjekut klinicist (internist), në lidhje me pacientët në stad terminal të sëmundjes, qasjen ndaj vdekjes si nga këndvështrimi i mjekut, ashtu edhe nga ai i pacientit dhe familjarëve të tij.

Metoda: Rishikim i literaturës dhe aspekte nga përvoja e punës në pavionin e Mjekësisë Interne dhe HTA, QSUT.

Përfundim: Ekziston nevoja e ndërtimit të protokolleve mjekësore dhe juridike në lidhje me kujdesin shëndetësor në fund të jetës. Gjithashtu nevojitet ngritja e qendrave të përkujdesit për të sëmurët terminal.

Fjalë kyç: në fazën e vdekjes aktive, kujdesi në fund të jetës, pacienti në fazën terminale.

Introduction

More and more deaths, especially in developed and developing countries, are occurring as a result of the slow progression of chronic diseases. Such a thing is inevitably associated with a long and sometimes slow process of the final period of life where vital functions gradually decrease and the patient can become dependent on medical devices and therapies, which often do not bring health benefits. Prolonging life with pain and suffering is unbearable for many patients and humanly and medically senseless. In order to adapt to the new situations with which reality confronts us, a not only practical but also logical and humane approach is needed in the treatment of the patient.

Concepts

In order to have a widely accepted understanding of the stages in which the chronic patient will pass on the way to the inevitable end, a standardization of terminology and concepts is needed for an easier communication between the physician and the patient and/or family members. Although a universally accepted definition of the following terms does not exist, I will try to give the most frequent meaning based on the reviewed literature.

Actively dying: the days or hours before imminent death, during which the patient's vital functions decline (1, 2).

Terminally ill is generally accepted as: life expectancy of 6 months or less (3).

Terminal care: medical care for individuals with a terminal illness from which death is expected within the next 12 months. Terminal care is about alleviating suffering (physical, spiritual, emotional, social) in the last phase of their life (3).

Palliative care is a medical service that improves the quality of life of patients (adults and children) and their families who face problems related to life-threatening illnesses. Palliative care prevents and alleviates suffering through early identification, assessment and accurate treatment of pain and other problems, whether physical, psychosocial or spiritual (4). Care provided to patients with symptoms resulting from incurable disease or a progressive disease with a short life expectancy. Palliative care is an active and comprehensive care model built on a clearly defined philosophy with the aim of meeting quality of life (QOL) requirements when curative therapy is no longer possible (5).

Hospice care: Hospice services provide supportive care in the home for patients with a life expectancy of less than 6 months. The focus of hospice care is patient comfort; treatment to extend life is not included (6). In providing active care of patients with advanced, progressive, and incurable diseases, hospice care: provides relief from pain and other distressing symptoms; enhances the quality of life when the length of life is limited; regards dying as a normal process; does not intend to hasten or postpone death; incorporates psychological and spiritual aspects of patient care; uses a team approach to provide a support system for patients and their families (7).

Dying with dignity: the most difficult concept to evaluate, because there are many definitions, from: an ethical concept aimed at avoiding suffering and maintaining control and autonomy in the end-of-life process. In general, it is usually treated as an extension of the concept of dignified life, in which people retain their dignity and freedom until the end of their life (8). up to euthanasia. Personally, I conceive dying with dignity as the patient's right to choose to die naturally, without pain, sometimes away from medical devices (pacemaker, ventilator, medical monitor), the right to choose not to perform life-saving maneuvers (do not resuscitate) and not to die in the hospital. The latter is also related to a widespread custom among Albanians not to let their family member die in the hospital, but at home surrounded by close family members and friends.

What are the pathologies that deserve palliative treatment?

When it comes to palliative care for patients, many people think of advanced cancer patients. But in today's medical understanding of palliative treatment, this concept is expanding more and more, either in the way of pathologies that deserve palliative treatment in the advanced stages of the disease or in terms of the time when this treatment can be started during the evolution of the chronic disease.

The National Institute for Clinical Excellence (NICE) emphasizes the importance of not only the best possible control of symptoms but also psychological, social and spiritual support for patients and their families (9). Today's view is that access to palliative care should focus on need and not diagnosis and on that criterion many patients with non-malignant diseases qualify as candidates for palliative treatment (10, 11).

Currently, palliative care, especially in developed countries, includes the treatment of advanced stages of the disease (and not only) in pathologies such as:

Oncological diseases: In advanced or metastatic stages, especially when they cause pain, fatigue, nausea, or other severe symptoms.

Cardiovascular diseases: Chronic heart failure. Cardiomyopathies in advanced stage.

Chronic pulmonary diseases: Chronic obstructive pulmonary disease (COPD). Pulmonary fibrosis. Severe pulmonary hypertension.

Neurological diseases: Alzheimer's disease and other forms of dementia. Parkinson's disease in advanced stages. Amyotrophic lateral sclerosis (ALS).

Cerebrovascular diseases (for example: the consequences of a severe stroke).

Hepatic and renal diseases: End-stage liver cirrhosis. Chronic renal failure, especially when dialysis is no longer effective.

Chronic or incurable infectious diseases HIV/AIDS in advanced stages. Incurable or drug-resistant tuberculosis.

Advanced rheumatological or autoimmune diseases: Severe systemic lupus. Rheumatoid arthritis in terminal stages.

Hematological diseases: Leukemias and lymphomas in incurable stages. Advanced myelodysplastic syndromes.

Pediatric incurable conditions.

Severe genetic metabolic diseases.

Congenital syndromes causing severe disability or limited life expectancy.

Because in the ward of Internal Medicine (UHC), the main focus is on the treatment of patients with heart failure, I will dwell a little longer on the palliative treatment of this chronic pathology with an inevitable fatal outcome.

Chronic heart failure

Anderson and colleagues compared symptoms in stage IV heart failure with those in advanced cancer and found that the most distressing were dyspnea and pain, respectively. (12) Various studies have shown that pain and dyspnea in end-stage heart failure patients are poorly controlled, even in hospitalized patients (13). Although the disease course of each patient with HF is unique, there is a general pattern of gradual decline, marked by episodes of acute worsening leading to either sudden death or death due to progressive HF. Communication about the inevitable progress of the disease and advance planning should begin as soon as a patient is diagnosed with advanced HF. Medical team-based approaches to palliative and end-of-life care have been proposed for patients with HF. Specific models of palliative care have been developed for patients with advanced HF. These initiatives aim to reduce hospitalizations, without a clear effect on survival, and have some effects on QOL and symptom burden (14). Progressive functional decline (physical and mental) and/or dependence in most activities of daily living accompanied by severe heart failure symptoms with poor QOL despite optimal pharmacological and non-pharmacological therapies are clear signs of end of life. Frequent hospital admissions or other serious episodes of decompensation despite optimal treatment constitute a clear indication to consider (14).

The main elements of palliative care service in patients with advanced heart failure focus on improving or maintaining the QOL of a patient and his/her family as much as possible until the patient dies. Frequent assessment of symptoms (including dyspnea and pain) is the main goal of medical treatment at this stage of the illness (14). It is important at this stage to discuss issues such as the place of death and life-saving maneuvers, which may also include the deactivation of medical devices such as: ICD (implantable cardioverter-defibrillator) and MCS (mechanical circulatory support) (14).

The difference between the terminal oncological and cardiac patient

Society's model of death originates in the trajectory of most cancer patients cancer: a long period of good vital functions, followed by a relatively short period of weight loss, and decreased vital functions. With the classic course of cancer, the average patient usually lives relatively well for up to two months before death. Once cancer becomes terminal, declines in vital functions and well-being is evident on a weekly basis, and death becomes quite predictable (15).

Patients with heart failure have a very different course at the end of life. Unlike cancer patients, these chronic patients have long-term limitations in functions with occasional early deteriorations, with hospitalizations where the clinical situation improves with treatment and a return to almost previous functional status is often observed (16). Doctors find it difficult to predict when a patient will deteriorate or, which episode will be fatal. Death in this course may seem sudden and unexpected for any patient, even though predictive models can derive an accurate survival curve for a large group of people with heart failure (15).

Perhaps also because the trajectory of heart disease is marked by many deteriorations and then improvements in the clinical condition, which makes the prognosis difficult, doctors rarely communicate with their patients about how they would like to live until at the end of life. This lack of comprehensive medical care planning causes patients to receive treatments such as intensive care and mechanical ventilation, even if they would have preferred otherwise (15). Determining the goal of treatment is particularly important for patients with heart failure, as, as the patient's disease worsens, the use of new technologies such as implantable cardioverter-defibrillators (ICD), resynchronization therapy, left ventricular assist devices, artificial hearts and even heart transplants all become therapeutic options. Clinicians must help patients weigh the benefits and burdens of medical interventions and devices in the impact they have on their lives (15).

In addition, as the clinical course of patients deteriorates, their cardiac function may deteriorate and cause multiple ICD shocks. Due to the progression of co-morbidities such as cancer or chronic pulmonary disease which will inevitably lead to death, continuous defibrillation can be distressing and pointless (17). Considering the likelihood that continued use of the ICD will become ineffective in prolonging life to an acceptable quality and providing workload while the chronic disease worsens, some patients may choose to deactivate their devices at the moment when their life is judged to be coming to an end (15).

When is the moment when the patient no longer benefits from medical treatment and should switch to palliative care?

In all the literature reviewed, there is no correct and exhaustive answer to this question. Although there are palliative treatment protocols for cancerous and non-cancerous diseases (National Consensus Project for Quality Palliative Care NCP, European Association for Palliative Care EAPC) which also provide an expanded panorama of clear end-of-life signs such as: decreased food intake and impaired hydration, death rattle, terminal delirium (without going into more detail as it is not in the focus of this material), no one defines exactly when it is the moment that medical treatment to go into palliative care. It should be emphasized that such a moment cannot be determined since in the concept of palliative medicine it can begin in the early stages of the treatment of the disease and can coexist with medical therapy for the purpose of recovery.

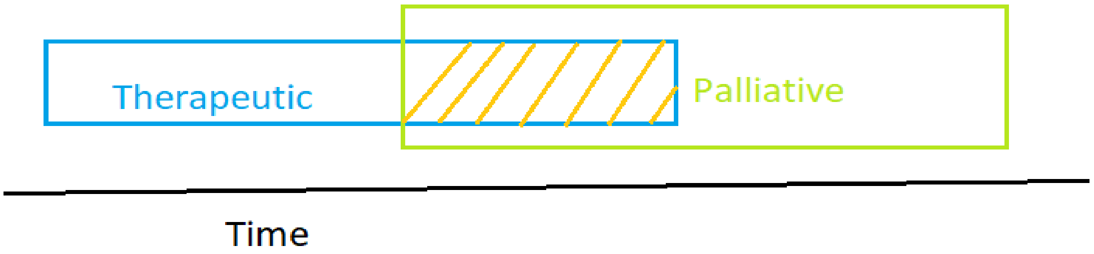

Figure 1. Therapies of terminal patient

Who does the assessment and where is it based?

Best practices based on the protocols of the American and British Palliative Care Associations emphasize the importance of decision-making by a multidisciplinary medical team in collaboration with the patient (when possible) and/or family members. The decision whether the patient should be transferred to hospice care centers for the continuation of palliative therapy, when it is judged that the further continuation of medical therapy with a therapeutic purpose is futile, should be taken by a group of experienced doctors.

The concept of hospice care: history, evolution and can it be applied in Albania

The concept of hospice care is closely related to the life and work of Cicely Saunders. Trained as a nurse during the Second World War in England, she then devoted her work to establishing care centers for cancer patients, to help relieve pain and make life as easy as possible and the easiest transition to the afterlife. Her work was sparked by an episode in her personal life where she cared intensely for her fiancé (a Polish immigrant with cancer) in the years immediately following the war (18).

In the following years, the objective of hospice care centers treatment was expanded to include, in addition to oncology patients, terminal cardiac patients and those with AIDS.

In Albania, to our knowledge, there was a hospice care center within a non-profit organization for a short period of time, which was then closed due to lack of funds. Currently, in our country, only a few centers of the Oncology Service at Home (SOB) (state) and some non-profit organizations are operating only for the help of the terminal patient treated at home. Regarding the palliative treatment of patients with non-cancerous diseases, there is no state medical organization or non-profit organization in this field.

Conclusion

With the increase in life expectancy and increasingly efficient treatments of various chronic pathologies, the number of non-oncological terminal patients has also increased. Such a situation has brought as the need of the time the medical and legal definition of new concepts regarding the treatment of patients at the end of life as well as medical protocols for treatment when medical therapy is judged to be worthless. Communication with the patient and/or family members of the diagnosis and its consequences, as well as the patient's life expectancy, are extremely important in relation to the progress of the treatment as well as the impact that the loss of a loved one can have on his family. The lack of hospice care centers where terminal patients can die with dignity and assisted by qualified medical staff (doctor, nurse) brings, in addition to the social and psychological traumas of the patients' families, an overload in the hospitals, especially in the capital. This is often associated with a deterioration of the doctor's image in general (especially in cases where terminal patients are not accepted for hospitalization).

Recommendation

The authors of this text recommend the definition of a legal framework related to the concepts discussed above to improve the approach, assessment and treatment of the non-oncological terminal patient as controlled as possible. This initiative requires the widest possible involvement of professionals from many disciplines (clinical doctors, nurses, psychologists, and lawyers, sociologists) in order to have a product as close as possible to the countries of the European Union, considering the customary, religious and social features of our country. The establishment and operation of hospice care centers for terminal oncological and non-oncological patients, to assist in the last stages of life. To introduce into the work practice in wards (Internal Medicine, Cardiology, Nephrology), making collegial decisions regarding the determination of patients who no longer benefit from curative medical therapy and can be transferred to palliative treatment at home.

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