Dignity of individuals with dementia, palliative care, and futile treatment

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Abstract
Case studies are used to reflect on the treatment of patients with dementia hospitalized at the Geriatric Department of the Faculty hospital in Prešov, emphasizing human dignity in clinical practice. The discussion is focused on the palliative care of patients with severe dementia. The biomedical method, which respects human dignity is defined by means of inductive, deductive, and normative bioethical methods. They make it possible to provide guidelines for palliative care and individualized prognosis strategy. An analysis of health status of individuals with severe dementia enables us to offer a clinical definition of purposeful treatment based on normative justice and decision-making that reflects the patient’s best interest, thus respecting their dignity. An evaluation of a patient’s care is based on a biomedical method that considers the dementia stage. Applying a bioethical model in a holistic context preconditions the human rights of patients with dementia.

Keywords: dementia, dignity of human being, palliative care, medical treatment futility, biomedical method.

Introduction
Dementia is one of the most significant epidemiological factor in the 21st century. Many people do not perceive it as a fatal and incurable disease (Stolička & Bužgová, 2012; Kumar & Kuriakose, 2013; Holmerová et al., 2010). The terminal dementia stage is the period when the disease passes to irreversible self-reliance in elementary self-care activities. This condition requires permanent all-encompassing nursing care (hygiene, dressing, food intake). Patients suffer from a severe and irreversible cognitive impairment; their communication is reduced to a minimum, and so is their eating and drinking capacity (Rusina et al., 2010). The terminal dementia stage lasts several months (usually, the last year of life), and, depending on the type of dementia and complications, it passes smoothly or suddenly into a terminal state, with a prognosis of several weeks (Holmerová et al., 2013). The dementia incurability is accompanied by the inevitability of the progression of the disease to an advanced stage. This condition requires palliative treatment. (Havlíčnová & Kabelka, 2010). Palliative treatment should be available to patients in the terminal dementia stage in the same way as it is available to oncological patients (Stolička & Bužgová, 2012).

Palliative care is multidisciplinary care combining the principles of medicine, philosophy, ethics, and law, and is directed at the essence of the human being. Philosophical principles underlying palliative care draw on the principles generally relevant to bioethics as a science. Humanism of the West-European culture is based on the inherent human being dignity as a fundamental principle of justice. In the European constitutional culture, the principle of human dignity is manifested in human rights as a “cultural gene of humanity” (Rendolf, 2014). Respect for human dignity plays a vital role in international documents. It is the defining principle of European bioethics. Dignity is generally perceived as the basis for all human rights; it is the essential material source of law regulating biomedical practice (UNESCO, 2005). Article 1 of the Convention on Biomedicine maintains the following: “Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine” (Council of Europe, 1997).

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And Article 2 states that “[t]he interests and welfare of the human being shall prevail over the sole interest of society or science” (Council of Europe, 1997). Human welfare can be interpreted as a spiritual good. The spiritual dimension of human life interrelates a person’s life’s bio-psycho-social and existential components. For religious people, religion is an expression of their spirituality. From the theological point of view, the patient’s dignity is based on the icon of the Absolute God. It becomes an ontological and anthropological category of bioethical reflection above the fundamental ethical, medical, and legal criteria of health care. The patient’s dignity is superior to all other goods (Balák, 2015).

**Dignity of individuals with dementia**

Human dignity from the point of view of ontological personalism includes four rights: the right to the protection of physical and psychological integrity, the right to autonomy in the sense of self-determination, the right to fundamental rights (especially human rights), the right to elementary respect for one’s personality. In a reductionist approach, Ulrich Körtner (2012) points out that, according to the image of a person fixed on knowledge and autonomy, people with dementia appear as people without dignity. Living with dementia is, according to this understanding, humiliating.

The bioethical objective consists in preserving the non-reductionist integrating approach to people with dementia. In everyday practice, they should be respected and they should feel recognition despite any cognitive losses.

**Bioethical principles and human being dignity**

The importance of bioethical principles and human dignity and their application is unquestionable, but their practical implementation is problematic. It requires an analysis of the bearer of reason, consequences, and application (Randall & Downie, 2006).

The dignity model specifies three main categories of factors that affect the patient’s dignity:
- The way the disease and the related problems influence dignity, the repertoire of the dignity-maintaining issues, that means the patient’s views and interaction with the environment.
- The questions and the perceptions with which the patient must cope. They include physical and mental disease manifestations and the patient’s reactions.
- The requirements to be met and the questions to be answered to the patient (Hack et al., 2004).

The biomedical method in clinical practice applies the dignity requirement of individuals with dementia by correlating bioethical principles and the dominant situational ethics according to the disease stage. The principle of normative autonomy is applied in the period of light dementia; the principle of normative justice prevails in later stages (Delmar et al., 2011). The biomedical reflection on human dignity according to the principle of autonomy and communication ethics requires recognition of autonomous abilities of patients with dementia in various disease stages. It lays emphasis on taking into consideration their decisions and respecting their right to autonomy even if they are not competent to make their own decisions. The biomedical reflection on dignity from the point of view of justice accepts in all medical procedures that individuals with dementia have in principle, the same right to medical therapy and care as any other person. Therefore, they cannot be discriminated.

In the terminal dementia stage, clinical bioethics aims to maintain human dignity by providing guidelines for palliative care and an individual prognostic approach. One of the most demanding decisions in medicine concerns the identification of the incurable stage onset. Unfortunately, the specification of the prognosis in patients with dementia is demanding because the condition oscillates. As a result, it is hard to distinguish between the terminal stage
onset and the aggravated patient’s condition due to the intercurrent, potentially curable disease (Lužný, 2013).

Guidelines for the palliative treatment and individual prognostic approach maintain that the correctness of an intervention decision is presupposed by precise documentation. Therefore, it should continuously evaluate the patient’s condition concerning their prognosis (Davidson et al., 2007). In patients with dementia, an aggressive medical approach may be detrimental for the patient. This raises the question of futile medical treatment (Rusina et al., 2010).

Futile treatment of a patient does not lead to saving the patient’s life, maintaining their health, or maintaining the quality of their life. Compared to the evaluation of treatment futility that also takes into account the patient’s preferences, unnecessary treatment is assessed by a doctor with corresponding expertise. In its document on medical treatment at the end of a person’s life, the European Council specifies the obligation to provide only adequate treatment: “Without prejudice to respect for the patient’s freedom and informed consent, the first prerequisite for the implementation or continuation of any treatment is a medical indication” (Council of Europe, 2014).

When applying physician judgment, scoring systems are likely more consistent than clinical judgment. Therefore, the severity of the disease should be determined using a combination of the clinical situation, laboratory findings, and scoring indices. In the case of terminal-stage dementia, we present an assessment of the medical effectiveness of the treatment as follows:

– The quantitative effectiveness of treatment should be assessed based on the presence of a terminal condition or in case of failure of organ systems even with their adequate treatment.

– Assessment of the qualitative effectiveness of the treatment based on the progression of the clinical condition with the worsening syndrome, negatively impacting the quality of life.

– The physiological effectiveness of the treatment should be evaluated on the basis of frailty indices when in the terminal stage of frailty, the patient’s physiological systems are in such a state that there is no available medical intervention that could reverse this trend.

– The concept of “medically useless treatment” eliminates the patient’s preferences. Therefore, from the point of view of clinical bioethics, it restricts the patient’s autonomy in severe dementia. From the point of view of medically unnecessary treatment, we apply the principle of normative justice as a bioethical reflection on human dignity (Delmar et al., 2011) (superior to the principle of autonomy). This is combined with the decision-making according to the patient’s best interest, which takes into account the patient’s expected quality of life as well as the ‘benefit-risk’ ratio from the patient’s point of view (Beauchamp & Childress, 2001; Novotný & Novotná, 2014).

The clinical procedure for the preservation of human dignity from the point of view of palliative care respects the fact that in persons with severe dementia it is necessary to give priority to the support of the current situation with the aim of pleasant sensations of the patient and the treatment of symptoms (Kruse, 2006). Treatments that require disciplined and long-term co-participation (e.g., dialysis, hospital stay) are likely to be burdensome for a person with severe dementia; it is also necessary, as far as possible, to refrain from coercive measures (fixation, forced diet, forced medication). As far as possible, it is necessary to avoid procedures that cause unpleasant sensations (e.g., probes, infusions, catheters), often associated with the need to immobilize the person.

Percutaneous endoscopic gastrostomy (PEG) is the introduction of a nutritional set to feed nutrition directly into the stomach via a catheter through the abdominal wall. Eating disorders are one of the symptoms of advanced dementia, with 6-month mortality in 25% of patients (Mitchell et al., 2009). Independent of age, patients with dementia with PEG in place had a worse prognosis than patients without PEG, with 54% mortality at 1-month post insertion and
90% at 1-year post insertion. The need for enteral nutrition and the prevention of malnutrition in patients with dementia is indisputable. Still, no data are supporting the fact that the introduction of PEG and nutrition through PEG improves survival in these patients. (Ayman et al., 2017). Thirty-day periprocedural mortality is reported to be 6.7-26%, with mortality figures being determined by patient comorbidities rather than the procedure itself (Ďurkovičová, et al., 2020).

Hypodermoclysis (HDK) is a subcutaneous application of infusion solutions. Hydration focuses on applying fluids to patients who cannot take food, especially fluids in a natural way or not enough. It replaces oral and intravenous administration of fluids (Sláma, 2008). Subcutaneous treatment is better tolerated by patients (even disoriented ones) since the subcutaneous cannula is less irritating, and the patient’s or limb’s movement is not necessarily limited. The introduction of the cannula is almost painless and well tolerated by patients, which improves the quality of life (Sláma, 2008). Chronic parenteral hydration support can be applied long-term or for life (Hozová, 2022; Zákon 267/2022 Z.z.).

Case reports of patients with the application of a biomedical method in a specific clinical situation in persons with dementia for the application of the dignity requirement

Case report 1
Hospitalization at the Geriatric Department 05. 2022
Epicrisis: 86-year-old patient from the Social Services Home (SSH), refuses liquids and food for a week. Admitted for severe dehydration, laboratory tests show severe metabolic derangement, hyperosmolar dehydration, renal insufficiency, the primary reason being acute upper respiratory tract infection acquired in the institution. Started rehydration treatment, targeted ATB treatment, comprehensive nursing care provided. Condition improved; the patient receives 1/3 of the daily diet, application of nasogastric tube not indicated. Hospitalization for 12 days.

Psychiatric conciliar examination: Dementia in Alzheimer’s disease, atypical or mixed form. No treatment recommended.


Clinical frailty scale: severely fragile (Rockwood et al., 2005).

Hospitalization at the Geriatric Department 06. 2022
Epicrisis: An institutionalized patient admitted after a change of residence from the new SSH, a week after being discharged from the Geriatric Department; she was taking food well; seven days ago, the condition worsened because of not taking food and fluids, repeated vomiting. The primary reason was an institution-acquired urinary tract infection. In the treatment, infusion therapy, antibiotics, symptomatic treatment, and nutritional support were applied. Due to reduced oral intake, a nasogastric tube was repeatedly inserted, with the repeated withdrawal
of the tube by an agitated, uncooperative patient. After stabilization of the patient’s condition, she receives 1/3 of the daily dose of food. Hospitalization for 7 days.

Psychiatric conciliar examination: Dementia in Alzheimer’s disease, unspecified. Recommendation: for the time being, without the need for psychiatric treatment, consciousness monitoring, or immobilization of the patient in case of significant restlessness.

Clinical diagnoses: Chronic pyelonephritis on the right with a functional kidney with acute exacerbation. Food and fluid intake disorder, urinary tract infection, and severe dementia. Dementia in Alzheimer’s disease, atypical or mixed form, other diagnoses as during the previous hospitalization.

Hospitalization at the Department of Internal Medicine 07. 2022
Epicrisis: An institutionalized female patient admitted to the Internal Medicine Department for an eating and fluid intake disorder. Laboratory results without more severe pathology. The patient receives 1/3 of the food dose. PEG insertion is planned for the patient, but relatives disagree with the insertion. The patient’s prognosis is unfavorable. Hospitalization for eight days.

Clinical diagnoses: Disturbance of food and fluid intake in Alzheimer’s dementia. Dementia in Alzheimer’s disease, atypical or mixed form and other diagnoses as during the previous hospitalization.

Hospitalization at the Geriatric Department 07. 2022
Epicrisis: Patient re-admitted for not taking food and fluids. At the beginning of hospitalization, the patient is restless; she repeatedly pulls out the permanent venous and urinary catheter. Finally, we approach the administration of subcutaneous hypodermoclysis, which the patient tolerates well. The patient receives 1/2 dose of a liquid diabetic diet. Hospitalization for ten days.

Psychiatric conciliar examination: This is a patient with severe dementia syndrome, with a decrease in cognitive and memory functions, who is unaware of the reasons for the planned necessary medical procedures. The patient cannot understand the meaning of the given medical procedure. The prognosis is dubious from a psychiatric point of view; the introduction of PEG will not have a significantly positive effect on her overall state of health and quality of life, but the decision to introduce PEG is purely within the competence of the indicating, treating somatic doctor – internist or geriatrician. Recommendation: Fixation of limbs (for necessary medical procedures) due to the lack of awareness of their own need.

Clinical diagnoses: Food and fluid intake disorder in Alzheimer’s dementia of a severe degree, other diagnoses as in the previous hospitalization. Recommended treatment: subcutaneous hypodermoclysis after breakfast – physiological solution of 500 ml, nightly application of glucose solution, 500 ml, possible adjustment according to the condition, nutritional support.

Stay at the SSH from 07. 2022 to 03. 2023
An 87-year-old, immobile patient feeds herself with half rations of food; hypodermoclysis applied within three weeks after discharge from hospitalization in the Geriatric Department. Currently, hypodermoclysis is not indicated.

Biomedical epicrisis: The patient’s organ systems did not fail during any hospitalization, and successful treatment of institution-acquired infections demonstrated quantitative efficacy. The clinical condition during repeated hospitalizations repeatedly showed improvement, and the disorder of fluid and food intake was temporary with a subsequent improvement in the quality of life; qualitatively, the treatment was effective. The frailty index showed a severe stage of frailty, but the patient benefited from the medical intervention, and the physiological futility of
the treatment was not proven. Conclusion: Acute treatment was fully indicated from a medical point of view; it was effective.

The primary repeated reason for the patient’s hospitalization was a food and fluid intake disorder, which in the case of the first two hospitalizations was related to the infection, dehydration, and probably to a repeated change of environment (stay in different social facilities with varying levels of nursing care). After rehydration, appropriate treatment of the infection, and stimulating nursing care, the patient’s mental state and alimentation improved. In the case of the other two hospitalizations, it was a disorder of food and fluid intake in connection with the basic diagnosis of severe dementia. The medical recommendation of PEG could be related to the effort to reduce the patient’s repeated hospitalizations due to dehydration, primarily due to the lack of evaluation of the effectiveness of treatment and complex biomedical reflection in relation to the basic diagnosis of severe dementia. The same can be said about the attitude taken by the consulting psychiatrists. The medical solution to the patient’s poor food intake was not the introduction of a PEG, not approved by the relatives either. The relatives had extensive information about dementia and showed great concern for the patient’s health. The patient was recommended hypodermoclysis in a SSH and was not hospitalized until now.

A hypodermoclysis is a tool for the prevention of dehydration in at-risk and palliative patients with dementia and for the prevention of iatrogenicity. In these patients, hydration support with hypodermoclysis reduces the number of hospitalizations in emergency departments. However, hospitalization is risky and often complicated. Moreover, it does not solve the problem of the patient with dementia in the long term, since after returning from hospitalization in an emergency department, the same problem with maintaining sufficient natural hydration persists.

Conclusion: The indication and application of hypodermoclysis were reasonable, in accordance with the application of normative justice and decision-making according to the patient’s best interest, and this procedure respected her dignity.

Case report 2
Hospitalization at the Geriatric Department 2016

Epicrisis: A 72-year-old institutionalized patient with dementia hospitalized for refusal of food and fluid intake. Psychiatric examination with the conclusion of dementia in Alzheimer’s disease, atypical or mixed form. The consulted neurologist recommended the introduction of a PEG, but the neurological findings during hospitalization remained unchanged. The patient’s relatives disagree with the proposed procedure, which they confirm by signing an informed consent. Upon discharge, the patient receives alimentation from half to one-third doses of porridge, crushed medicines, and assistance with feeding. Hospitalization took 13 days.

Hospitalization at the Geriatric Department 2018

Epicrisis: A patient hospitalized in the Geriatric Department with proven dementia of a severe degree, institutionalized, immobile for a long time, sent to hospitalization for refusing food and liquids. During hospitalization, enteral nutrition was ensured by an inserted nasogastric tube. Considered introduction of PEG, consulted with psychiatrist, and neurologist, who indicate PEG in case of persistent problems. Laboratory results show increased inflammatory parameters. Development of bronchopneumonia on the right side based on microaspiration. After a collective evaluation of the condition, we did not indicate the application of PEG.

Conciliar psychiatric examination: Dementia in Alzheimer’s disease, atypical or mixed form, does not require treatment. Indication: introducing PEG from a vital indication is within the competence of a specialist in the given field.

Conciliar neurological department: Dementia in Alzheimer’s disease, atypical or mixed form. Multi-infarct encephalopathy and other diagnoses. If the patient does not take food and
there is no prospect of improvement, the introduction of a PEG is fully indicated. On the 14th day of hospitalization, the patient was transferred to the Department for Long-Term Care Patients to continue treatment.

**Hospitalization at the Department for Long-Term Care Patients 2018**

*Epicrisis:* The patient continues antibiotic treatment for pneumonia, another infectious nosocomial complication occurs – an intestinal infection caused by Clostridium difficile. A PEG was inserted into the patient. Complex therapy continues, the condition progresses, and the patient dies of bilateral hypostatic pneumonia. Hospitalization lasted 28 days.


*Clinical frailty scale:* very severe frailty (Rockwood et al., 2005).

*Biomedical epicrisis:* The quantitative ineffectiveness of the patient’s treatment was manifested by the failure of infected organs even with their adequate treatment (bilateral pneumonia, chronic nephritis with infection, ineffectiveness of continued antibiotic treatment, associated infectious enteritis acquired in the hospital). The qualitative ineffectiveness of the treatment was demonstrated by the progression of the clinical condition with the worsening syndrome, a persistent disorder of fluid, and food intake, with a negative impact on the quality of life. The frailty index manifested the physiological ineffectiveness of the treatment in the stage of very severe frailty; the patient’s physiological systems were in a state of progressive deterioration.

*Conclusion:* Acute treatment and acute interventions until the patient’s death were medically ineffective.

Non-discrimination and respect for autonomy of patients with dementia do not mean that they will be provided with every therapeutic and nursing intervention that is meaningful for non-demented patients. The principles of beneficence and nonmaleficence refer to the physician’s double duty to maximize the potential benefit and limit any harm that may result from medical intervention as much as possible. The balance between benefits and risks of harm is of key importance (Council of Europe, 2014).

In the patient’s case report, the neurologist and the psychiatrist recommended the indication of PEG in isolation based on the symptom (disorders of food and fluid intake), but not in the context of the underlying disease of advanced dementia with complications, without evaluating the prognosis of the clinical condition from the point of view of the effectiveness of the treatment. This statement also applies to the decision to introduce PEG. If the doctor evaluates the condition of a chronic patient primarily on the basis of the possibility of actual implementation of medical interventions without evaluating the overall condition of the patient (based on the disease stage, the extent of the disability, and the severity of clinical symptoms) the medical ineffectiveness of treatment is not used as a reason for withdrawing from continued treatment (Novotný, Novotná & Andraščiková, 2020).

*Conclusion:* The indication and application of PEG were not reasonable, it was not in accordance with the application of normative justice and decision-making according to the patient’s best interest; this procedure violated the patient’s dignity.
Case report 3
Hospitalization at the Geriatric Department in 2019

Epicrisis: An 89-year-old female patient hospitalized at the Department of Internal Medicine and Geriatrics of the Faculty hospital in Prešov with a documented basic diagnosis of severe vascular dementia, chronic heart weakness, immobile, pressure ulcers acquired in a community. Brought from home for dehydration due to not taking food and liquids. The patient does not communicate; the clinical picture is dominated by a quantitative disorder of consciousness (at the level of sopor), which persists throughout the entire period of hospitalization, hypotension. Dehydration is evaluated as the consequence of the refusal of fluid and food intake in severe dementia with impaired consciousness. Parenteral rehydration therapy administered for 14 days, parenterally modified internal environment, parenteral antibiotic treatment for respiratory infection, oxygen therapy. When the laboratory parameters improve, the clinical condition remains unchanged, and the disorder of consciousness worsens to the level of coma. We determine the terminal condition of the underlying disease, which was vascular dementia; based on an agreement with the relatives and by collective assessment of the clinical condition, we approach palliative care; we retreat from complex parenteral treatment and apply hypodermoclysis; we provide complex nursing care. In the treatment, we do not choose analgesics due to the absence of clinical or pain scale symptoms. On the 28th day of hospitalization, we make a physical diagnosis of bilateral bronchopneumonia, a metabolic disorder present in the laboratory. We do not proceed with antibiotic treatment. On the 31st day of hospitalization, we state a fatal exitus. We do not consider resuscitation by the prior entry in the documentation.

Clinical diagnoses: Vascular dementia in the terminal stage with a transition to the terminal state, a quantitative disorder of consciousness of a severe degree. Terminal geriatric deterioration syndrome: cachexia, immobilization syndrome, permanent urinary incontinence, pressure ulcers on both lower limbs.

Clinical frailty scale: terminally ill (Rockwood et al., 2005).


Biomedical epicrisis: Quantitative futility of the patient’s treatment was manifested by progressive failure – a disorder of consciousness at the basic diagnosis of terminal dementia with a transition to the terminal state with complete acute therapy for 14 days. The qualitative ineffectiveness of the treatment was demonstrated by the progression of the clinical condition with worsening syndromology, a persistent disorder of consciousness, a disorder of fluid and food intake, with a negative impact on the quality of life. The physiological futility of the treatment was demonstrated by the frailty index; in the terminal stage of frailty. The patient’s physiological systems were in such a state that no medical intervention was known that could reverse this trend.

Conclusion: We did not proceed with continued acute (aggressive) treatment and cardiopulmonary resuscitation; it was useless in the terminal stage of dementia.

The primary reason for the patient’s hospitalization was the food and fluid intake disorder. Reduced food intake in patients with dementia may signal the entry of a person with severe dementia into the terminal phase of the disease, as was the case with our patient. The solution to poor food intake in these patients is not the introduction of a gastric tube or PEG (Palecek et al., 2010; Chung, 2013; Kumar & Kuriakose, 2013; Holmerová et al., 2006). After a collective
assessment of the patient’s condition, we did not introduce a nasogastric tube or PEG. Palliative treatment for a patient with severe dementia in the terminal condition should aim at a comprehensive treatment of symptoms (Lužný, 2013; Holmerová et al., 2013). From the point of view of the essence and goals of palliative medicine (Stolička & Bužgová, 2012; Holmerová et al., 2010), overly aggressive treatment was not chosen (Kumar & Kuriakose, 2013). Since communication with the patient had disappeared entirely, we paid attention to non-verbal expressions (Holmerová et al., 2013; Holmerová & Vaňková, 2005). We paid attention to pain symptoms, even though diagnosing pain in patients with dementia is very difficult (Holmerová et al., 2009; Chang et al., 2008; Volicer & Kršiak, 2006). To assess pain, it is recommended to use scales created for patients with dementia (Long, 2009; Volicer & Kršiak, 2006; Holmerová et al., 2009; Torvik et al., 2010; Jordan et al., 2010). The cooperation of the entire participating team was necessary to ensure nursing care (Chang et al., 2009; Rusina et al., 2010). We allowed the patient’s family to visit their dying relative. The basic goal of palliative care for our patient was not to prolong life but to ensure comfort (Palecek et al., 2010).

Dying with dignity includes the right not to suffer, the right to routine symptomatic treatments, the right to the truth and the right to autonomy. A terminally ill patient should be helped to live the last part of his life with dignity; they have the right to live their dying life with dignity and freedom. Concerning intensive therapy, the Catechism of the Catholic Church says that the interruption of expensive, dangerous, extraordinary or, in view of the expected results, disproportionate treatment procedures may be justified. It means the rejection of “the treatment at any cost”. Refusal of such a fierce struggle for life becomes legitimate and obligatory as a manifestation of authentic responsibility and respect for human life (Faggioni, 2012).

Conclusion: Failure to insert a gastric tube and PEG was in accordance with the application of normative justice and decision-making according to the patient’s best interest. This procedure respected the patient’s dignity.

Guidelines

The guidelines for the decision-making process concerning medical treatment in end-of-life situations developed by the Committee on Bioethics of the Council of Europe state that the rights and dignity of the human being with regard to the application of biology and medicine form the ethical and legal frame of reference through which Member States seek to find common, coordinated answers to questions that arise in society, to ensure the protection of human dignity. Based on shared values, these provisions can be applied to end-of-life situations addressed by medical care and health systems. Respect for the dignity and autonomy of the individual must be the central theme of any discussion about decisions regarding medical treatment (Council of Europe, 2014). The Convention on Biomedicine accentuates the autonomy of the human being and, at the same time, emphasizes the abstract value of human dignity. The autonomous patient model with enhanced patient decision-making rights should be applied with a balance of freedom and responsibility. Public ethics at the level of individual European states and the use of traditional models conditions the application of the Convention on Biomedicine, which is a framework guide for fulfilling the biomedical dimension of the concept of human dignity.

The main social deficits in connection with the diagnosis of dementia include insufficient information about the disease, fear of dementia, failure to overcome prejudices, and exclusion and stigmatization of persons with dementia (Chung, 2013). The Slovak Republic does not have legislative mechanisms that enable a person to decide autonomously at a time when they still have autonomy about what is or will no longer be dignified, unacceptable, what they do not want, as well as to prevent situations when a person after a complete loss of autonomy would be dependent on the decisions of others. However, although there is no institute of previously
expressed wishes of patients in the legal order in Slovakia, the Convention on Human Rights and Biomedicine contains this legal institute, and is therefore applicable in the Slovak Republic. Clinical practice in the Slovak Republic does not experience court appeals in standard clinical procedures for this type of situation (no such case has occurred in the case-law of the Slovak Republic) (Firment, 2015). If transparency is defined as the provision of information for public access (Jöbges et al., 2020), the principle of transparency in decision-making is not implemented in the public health sector of the Slovak Republic, allowing patients and relatives to understand how clinical decisions are made.

The task of bioethics is to help in coping critically with the one-sided idea of man, whose essence is performance, rationality, autonomy, and individuality. The ability to act and receive is as valuable as the ability to create. Illness and suffering belong to our life, just like health. Being dependent on others is just as dignified as autonomy and independence (Körtner, 2012). The general bioethical rule for human dignity and the development of a spiritual model of a “dementia-friendly” society requires a change in the existential consciousness of man. This is conditioned by the development of an individual and social (cultural) model and a scaled (bioethical) education of professionals who take care of patients with dementia and relatives of these patients.

The bioethical model for palliative care of a patient with dementia from the point of view of general bioethics employs the dominant theory of the ethics of responsibility, compassion, and theological ethics for religious people and relies on the interaction with the ethics of casuistry, communication, and nursing. The dominant goal is to preserve the dignity of a patient with an incurable disease. The main principles are humanity, autonomy, and justice. The ethical process of general bioethics uses methodological pluralism. The professional approach of clinical bioethics uses an individualized prognostic strategy and expert guidelines for supportive and palliative care. The palliative strategy aims to manage the process of incurable diseases in the bio-psycho-socio-spiritual and existential context of the patient. The global bioethical goal is defined as a paradigm of solidarity and social justice. According to John Paul II, the principle of solidarity is described as follows: “It is above all a question of interdependence, sensed as a system determining relationships in the contemporary world, in its economic, cultural, political and religious elements, and accepted as a moral category. When interdependence becomes recognized in this way, the correlative response as a moral and social attitude, as a “virtue,” is solidarity.... The exercise of solidarity within each society is valid when its members recognize one another as persons” (John Paul II, 2011). The ethos of helping and humanity is fundamentally based on the experience of our vulnerability and that of others. Mutual dependence on help is not a deficiency but, on the contrary, an essential prerequisite for the fulfillment of human life and human existence on earth.

References


