CHAPTER 74

END-OF-LIFE CARE: A CRITICAL-REFLECTIVE REVIEW OF HOSPITAL PRACTICES

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ABSTRACT

The objective of this study was to reflect on the principles of autonomy and dignity of the person, relating them to health ethics in hospital practices. The individual has the

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opportunity to plan in advance the care of his health through advance directives of will. In the doctor-patient relationship, this principle is fundamental where it replaces the old authority of the physician with the consideration of the patient as an active participant in the treatment process, however some physicians face difficulties in discussing end-of-life issues due to factors such as personal discomfort, lack of time, insufficient training, limited resources, or the perception that patients may feel uncomfortable. In this sense, we present a theoretical and practical construction of these principles and their benefits in quality of life. Although in Brazil there is no law regulating advance directives, the Federal Council of Medicine published Resolution 1995/2012 in which it guides advance care planning to facilitate the work of the health team in the face of complex ethical dilemmas from the beginning to the end of life as the basis of shared care decisions.

Keywords: Autonomy. Dignity. Terminality. End of Life Care.

INTRODUCTION

DIGNITY OF THE PERSON AND ITS RELATIONSHIP WITH BIOETHICS AND BIOLAW

The word Bioethics, from the Greek *bios* (life) and *ethos* (related to ethics), involves the Biological Sciences, Health, Philosophy (Ethics) and Law (Biolaw). Its responsibility is to regulate conducts related to human and animal life and the environment (SOARES & PINEIRO, 2006). The principles of bioethics and biolaw, with a focus on the dignity of the person, are intrinsically linked to the autonomy of the patient's will. The latter must have his will and dignity assured in matters related to his own health. Biolaw seeks solutions to conflicts in this area and imposes limits on the performance of health professionals. It therefore establishes guidelines for making difficult decisions, ensuring that the patient's will is preserved and respected, in accordance with the rights of personality and human dignity.

The principle of the dignity of the person is guaranteed in article 1, item III of the Federal Constitution (BRASIL, 1988) and is inherent to man himself. The right of personality seeks to protect this principle of individual value, unique and essential to every person, ensuring the guarantee of a dignified life, being, therefore, the fundamental source of all rights (BRASIL, 1988). In the health area, information related to the patient belongs exclusively to him or her due to his or her right to intimacy, private life, honor and image, with the legal support of article 5 of the Federal Constitution (BRASIL, 1988).

Scientific and technological advances in biomedical sciences have made it possible to carry out unprecedented interventions, such as assisted reproduction, organ transplantation, genetic engineering, among others. Therefore, they made inevitable "ethical questions related to the limits of application of such biotechnologies" (CONTI & SOUZA, 2021, p.717).

The objective of this study was to reflect on the principles of autonomy and dignity of the person, relating them to ethics in health, personality rights and the benefits to patients in the scenario of terminal life and in medical conditions that reduce functional capacity, articulating theoretical, clinical and cohort studies to illustrate the connections between legislative support, course of medical treatments and quality of life.

Human dignity is related to the rights that all people have, simply because they are human. "... the recognition of the inherent dignity of all members of the human family and of their equal and inalienable rights is the foundation of freedom, justice and peace in the world..." (UNITED NATIONS [UN], 1948, p.1).

The Universal Declaration of Human Rights (UN, 1948) was drafted to ensure broad protection for people, as citizens with civil, political, social, economic and cultural rights. It has become the duty of the State to ensure the protection of the person as a subject capable of making decisions and expressing himself freely. In its article 1, it highlights: "All human beings are born free and equal in dignity and rights. Endowed with reason and conscience, they must act towards one another in a spirit of fraternity".

THEORETICAL FRAMEWORK

HUMAN RIGHTS IN BIOETHICS: A UNIVERSAL DECLARATION

Bioethics, a term coined by the German theologian Fritz Jahr in 1927 (GOLDIM, 2009), developed in the second half of the twentieth century. and individual rights linked to the exercise of freedom and personal autonomy" (CONTI & SOUZA, 2021, p.717). The contestation of the power of institutions led to important changes, which also affected the medicine practiced at the time, characterized by paternalism and abuses in research with human beings (JONSEN, 1998 apud CONTI & SOUZA, 2021).

Another factor responsible for the development of bioethics was the impressive technical-scientific evolution, which enabled effective interventions in the health area, such as drugs and sophisticated diagnostic and surgical procedures. "This picture, in addition to transforming knowledge about life, highlighted the promises and dangers of the new biotechnical powers, since the human being, from a mere spectator, became the master of biological evolution" (CONTI & SOUZA, 2021, p.717).

The General Conference of the Universal Declaration on Bioethics and Human Rights consciously deliberates and recognizes the ethical issues arising from rapid advances in science and its technological applications. These issues must be examined with due respect for human dignity and in accordance with universally recognized human rights and fundamental freedoms (UNITED NATIONS, 2005).

THE PRINCIPLES THAT GOVERN BIOETHICS

The Universal Declaration of Bioethics and Human Rights is governed by principles that must be respected in the field of bioethics in its articles 3, 4, 5 and 6, which are: human dignity and human rights, benefit and harm, autonomy and individual responsibility and consent (UNITED NATIONS, 2005).

Human dignity is a central concept in human rights. The Universal Declaration of Human Rights, adopted in 1948 by the United Nations General Assembly, recognizes that dignity is inherent in everyone. Therefore, the protection of life, liberty and personal security is essential to guarantee it.

In addition, Article 4 highlights the importance of maximizing the benefits and minimizing the harms related to the application of scientific knowledge, medical practices, and technologies. This means that when advancing in science and medicine, we must prioritize the well-being of patients, research subjects, and other individuals (UNITED NATIONS, 2005).

The four principles of bioethics

From the relationship of humanization of medical care, we can conceptualize each principle. First, the principle of autonomy is respect for the patient as an autonomous person. The patient has the freedom to want to be treated or not, to want to live with quality or to die with dignity (BRASIL; MINISTRY OF HEALTH; SECRETARIA DE ASSISTÊNCIA À SAÚDE, 2001). As long as all points related to their health are clarified, such as forms of treatment, diagnosis and procedures, considering all the possibilities of the best available treatment for the patient's health and well-being (KOVACS, 2009).

According to Naves and Sá, the principle of autonomy recognizes that people have the capacity to govern themselves. In the doctor-patient relationship, this principle is fundamental. It replaces the old authority of the physician with the consideration of the patient as an active participant in the treatment process. To ensure that the patient has all the necessary information, it is essential that the intervention process is transparent. Therefore, informed consent is required, allowing the patient to make well-informed decisions (NAVES & SÁ, 2018).

In view of the principle of non-maleficence, it is established that the doctor's action must be as harmful as possible to the patient's health, that is, the doctor must try to reduce as much as possible any effect of the treatment applied (MAXWELL et al., 2012). As for beneficence, the doctor has the ethical duty to cause as little harm as possible to the patient. Based on this context, we can highlight that the autonomy of the person over their own body overrides the principle of beneficence (PARSONS & CARVALHO, 2014)

The paradigm of medical paternalism, which had previously prevailed, has gradually been overtaken by patient autonomy. In contemporary and secularized society, the applications resulting from biomedical research generate dilemmas for the professional practice of physicians. Today, doctors allow patients to express their wishes, either spontaneously or through a document (PARSONS & CARVALHO, 2014).

Ethical medical intervention takes into account not only clinical aspects, but also personal values. This approach aims to ensure that the treatment is aligned with ethical principles and respects the dignity of each individual (SATO, 2023).

THE PRINCIPLES OF BIOLAW

Biolaw is based on three specific areas of Law: Constitutional, Civil and Criminal. The Constitutional Law and its fundamental rights to life, liberty, health and intimacy. The Civil has a direct relationship with personality rights. Article 13 of the Brazilian Civil Code establishes that, except when necessary for medical reasons, it is forbidden to perform any act that causes a permanent decrease in physical integrity or that goes against good customs, involving one's own body. Article 15, on the other hand, ensures that no one may be forced to undergo medical or surgical treatment that puts their life at risk (BRASIL; CIVIL CODE, 2002). These provisions aim to protect the autonomy and dignity of individuals in relation to decisions about their own bodies.

As we can see, the direct relationship with these branches of Law and Biolaw is notorious in the search for existing legal systems to assist in the solution of conflicts between science and people in general (PARISE, 2011). Thus, the principles of precaution, private autonomy, responsibility and dignity are considered for conflicting decisions.

The precautionary principle is related to preventing and avoiding acts that threaten to cause damage to the environment and human health, having a direct relationship with the principle of beneficence and non-maleficence (LAPA, 2002). For Francisco Amaral, private autonomy is the principle by which the agent has the possibility of performing a legal act, determining its content, form and effects (AMARAL, 2000). The principle of responsibility implies the obligation to indemnify the offended party with a sum of money, in order to sanction the offender and satisfy the victim (FARIAS et al., 2014).

Finally, the Federal Constitution of 1988 expressly brought the dignity of the person in its first article that establishes the foundations of the Brazilian State. This principle is central to the understanding of fundamental rights and aims to protect the integrity and well-being of individuals. Dignity is the foundation that unites the essential rights conferred on citizens. It serves as a constitutional reference to ensure the comfort and protection of people, preventing them from suffering injustice or inhumane treatment (CAVALIERI, 2010; FARIAS et al., 2014).

PERSONALITY RIGHTS

It is important to emphasize that there is no exhaustive list of personality rights, as these rights are under constant construction and are understood as general clauses for the protection of the person. The Civil Code establishes that, except in the cases provided for by law, personality rights are non-transferable and non-waivable. Thus, any violation of these rights can be sought in court, either by compensation or protection measures. The protection of personality rights is fundamental to guarantee human dignity and individual freedom (DONEDA, 2003; MATTIA, 1977).

NARRATIVE AND CRITICAL REVISION

WHAT ARE THE BENEFITS OF THE APPLICABILITY OF THE PRINCIPLES OF BIOETHICS AND BIOLAW IN HOSPITAL PRACTICES?

The terminally ill patient is defined as one diagnosed with an expectation of death within a few months, with no possibility of fundamental recovery, and whose symptoms gradually worsen despite proactive treatment. The diagnosis of terminal illness is restricted to four types of diseases: cancer, acquired immunodeficiency syndrome (AIDS), chronic obstructive pulmonary disease (COPD) and chronic liver cirrhosis (CL), as established by the ordinance of the Ministry of Health and Welfare. The patient in a period of death, on the other hand, is one in a state of imminent death, in which there is no possibility of revitalization or recovery, and whose symptoms worsen rapidly (LEE et al., 2021).

End-of-life care and limiting conditions in pediatric patients involves more than one person, and those responsible are also part of the decision about the treatment of the child and adolescent, and conflicting wills may arise. The PPC [pediatric palliative care] protocol introduces those responsible together with the patient to the possibilities in the face of the available resources, being a method of listening, welcoming, technical positioning and questioning about the patient's desires, wants and needs, articulating what can be solved and what cannot. Articulations and informed decisions come from the diagnosis and recommendations of the multiprofessional team. The protocol demonstrated, in a retrospective study, effectiveness in promoting the well-being and quality of life of parents and patients by promoting information and assistance in decision making, however there were cases of non-questioning of end-of-life wishes, observing failures in the application of the PPC interfering in the autonomy of those involved and hypothetically submitting to costly treatments (PELÁEZ-CANTERO et al., 2023).

Research on paediatric palliative care has illustrated the importance of a well-structured protocol to ensure informed decisions and respect the autonomy of all involved. The aforementioned retrospective analysis offers evidence on the effectiveness of PPC, but also highlights the need for continuous improvements to avoid gaps in practices, modulated by bioethical and biolaw principles.

Considering adult and elderly patients, chronic diseases have been increasing in Brazil and worldwide. Focusing on Brazil, the authors present the need to discuss with the patient the care of the dying process, establishing the necessary care. However, there is no legislative support because the legislation focuses on treatment and cure, preventing the health team from debating issues of the end-of-life process with the patient. Non-dialogue increases hospitalizations and invasive and unnecessary treatments, observing a clash between Evidence-Based Practices in End-of-Life-Care and Brazilian Medical Ethics. The authors identified that terminally ill patients were in inpatient units undergoing costly treatments, even though there are other guidelines in the literature, especially Palliative Care, noting a lack of knowledge of such measures in Brazilian practice (LIN et al., 2023)

Palliative Care in Adults and the Elderly evidences a conflict between evidence-based practices and local medical ethics, suggesting an urgent need for legislative and educational reforms. The correct identification of terminally ill patients together with knowledge of the guidelines can help to redefine palliative care in the Brazilian context.

There are benefits in quality of life when autonomy is achieved with the patient through information and dialogues about being submitted to treatments, but for the decision not to treat it is necessary to have support in the legislation. This study took place in Victorian, Australia, bringing an analysis of the perception of a patient who followed the change in legislation on informed decision and autonomy, prevailing the dignity of life and respect for personality. Victorian's experience serves as a relevant case study for other regions, demonstrating that legislative changes can lead to significant improvements in end-of-life care. This example can inspire reforms in other jurisdictions (GILBERT & BOAG, 2019).

A CRITICAL ANALYSIS OF DEATH AND DYING

It is essential to promote continuity in the provision of end-of-life care by a fixed, qualified and stable team of health professionals, as this facilitates a doctor-patient relationship of trust and allows more time to discuss topics other than clinical needs. More home care services and palliative care centres are needed, combined with effective communication to facilitate access to specialist care and the transition to end-of-life care (LUNA-MEZA et al., 2021).

Autonomy in the United States is considered one of the four ethical principles that guide critical medical decision-making (MACKLIN, 2003 apud KIM et al., 2021). Unfortunately, patients without advance directives may receive aggressive treatments that are not aligned with their care goals, which can exacerbate suffering. Some clinicians face difficulties in discussing end-of-life issues due to factors such as personal discomfort, lack of time, insufficient training, limited resources, or the perception that patients may feel uncomfortable, frustrated, or stressed when addressing terminal care measures (BIONDO et al., 2019 apud KIM et al., 2021)

It is amazing how human beings often act as if they were immortal, ignoring the inevitability of death. The quest to prolong life at any cost is an intrinsic characteristic of our nature. However, this search does not always consider the impact it can have on others and sometimes even goes against the wishes expressed by sufferers. In most cases, death is the result of a long journey marked by chronic and debilitating diseases, such as late-stage cancer, dementia, and progressive failure of vital organs. "In all these cases, death is certain." (GAWANDE, 2015, p. 150).

The quote from author Atul Gawande makes us reflect on how we deal with death in our society. Even in the face of evidence of the benefits of talking about it, we often resist accepting it. It is essential to consider the quality of life and wishes of patients when facing serious illnesses, seeking a balance between prolonging life and ensuring dignity and comfort.

Palliative Care has been debated around the world for several decades, but we are still constantly evolving. In Brazil, we are just beginning a change in the way we think and accept our finitude (ARANTES, 2020, p. 62).

Resolution 1995/2012 of the Federal Council of Medicine (CFM) addresses the issue of the autonomy of the patient's will. This autonomy is intrinsically linked to the dignity of the person. It is sovereign and is based on principles such as equality, non-discrimination and the recognition that all people are subjects with rights. Health professionals have responsibilities towards patients, and in this context, new rights arise that must be considered. Among these rights, the exercise of individual freedom, self-determination, and autonomy stand out, allowing each individual to make decisions related to health care. These values are essential to preserve human dignity (RESOLUTION 1995/2012 of the FEDERAL COUNCIL OF MEDICINE, 2012).

Ana Michelle Soares, author of "While I breathe" – (2019, pg. 14), reports the importance of a clear conversation with your doctor about your real state of health. In her book, she tells her story (of her cancer diagnosis, her choices and what was most important: living her last days intensely and with quality of life) and her friend Renata (also diagnosed with metastatic cancer): where they take control of the treatment, make their own choices and in their routine explain what palliative care is: "Palliative care is not about dying, it's about how to live (until then).", when the end is near. In fact, they are about living fully until the last moment.

It is essential that the doctor explains to the patient what his real health status is and provides all possible information about the treatments, clarifying doubts related to medications and exams. Only through a clear, sincere and objective conversation will the patient have the freedom to make their own decisions.

To guarantee these principles in daily life, it is necessary to encourage families to talk about end-of-life care in order to instrumentalize the living will so that it has the quality of death (KIM & PARK, 2021). Other authors reinforce that advance planning of end-of-life care is one of the most important aspects of palliative care (PELÁEZ-CANTERO et al., 2023).

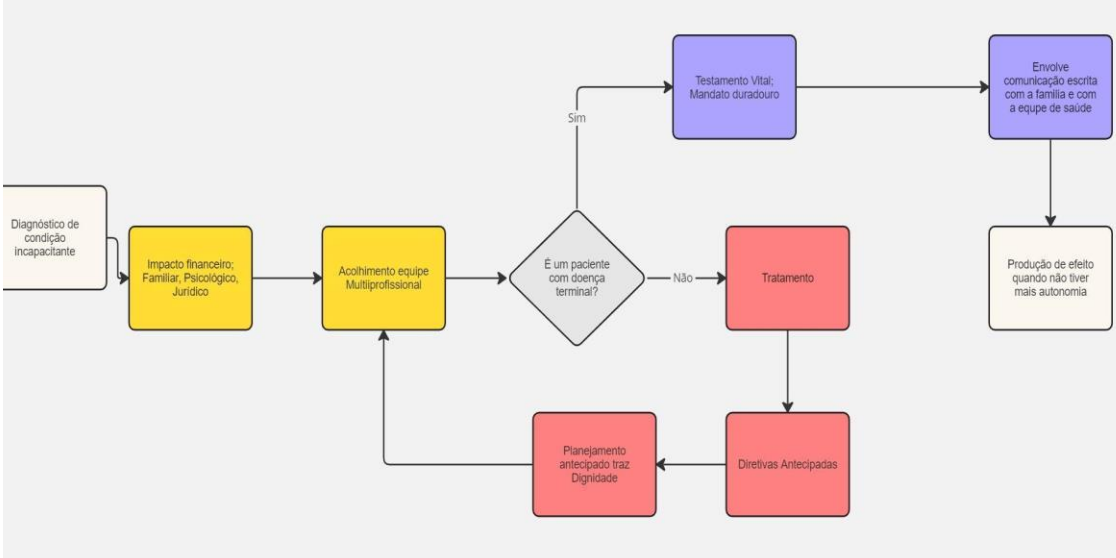
In the final stretch of life, often shrouded in uncertainty and fear, it requires a frank and sensitive dialogue between patients and health professionals. However, communication about desires and choices at this crucial moment comes up against several difficulties, compromising the patient's autonomy and the quality of their last days (KUUSISTO et al., 2022).

A PROPOSAL FOR A CARE PROTOCOL

Based on the legislative proposals and research cited in our study, which address vulnerability or its possibility in the life course, we developed a decision-making flowchart after the diagnosis of transient or chronic disabling disease, as well as considering the prognosis of terminality.

Figure 1 shows the existence of the disease condition, that is, performed by the medical team, which must activate the multidisciplinary team to support the financial, social, legal and psychological needs of the following guideline. It is important to highlight the need for the team to question whether it is a patient with a chronic or terminal disease so that palliative care can be performed, as well as to delegate decisions when the patient no longer has autonomy, with multiprofessional support in the delegation and with a written report. Finally, if the patient is conscious and with full civil capacity, it is recommended to carry out the Advance Directives of Will for the advance planning of care in relation to their health. In this sense, integration and communication between professionals and also with family members is required to improve everyone's quality of life.

Figure 1. Implementation of Humanization of Care for Patients with Transient or Chronic Disabling Diseases with Suspected/Confirmed Terminality



Source: prepared by the authors

CONCLUSION

The discussion is comprehensive and addresses the main challenges and needs in palliative care. The focus on education and the development of specific infrastructure is essential to improve the quality of life of patients. Promoting effective communication is crucial to ensure that patients can make informed and dignified decisions. Reflection on the patient's autonomy is urgent in time. The work of Atul Gawande, the personal experience of Ana Michelle Soares and the research presented show us that autonomy is seen as a fundamental ethical principle that must be respected to guarantee the dignity and quality of life of patients with terminal illnesses. Thus, health is distributed in an ethical and fair manner, alleviating the pain and suffering that the individual faces at that moment. Therefore, the principles of bioethics play a fundamental role in this whole context.

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