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Terminal care: philosophical reflection from ethical and moral perspectives

Cuidados terminais: reflexão filosófica sob a ótica da ética e da moral

Cuidados terminales: reflexión filosófica desde la perspectiva de la ética y la moral

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ABSTRACT

Objective: To reflect on the care practice for patients with a terminal illness from ethical and moral perspectives. **Method:** This is a theoretical-reflective study carried out from the critical analysis of philosophical texts on ethics and morals in the context of human moral development and health practices. **Results:** At the time of Greek philosophers, ethics was based on the search for happiness. However, with the advent of Christianity, this came to be seen as a duty. According to Kant, ethics and morals are duties as well — a categorical imperative — and the life maintenance issue must be pursued, opening space for the occurrence of dysthanasia practices. From Hans Jonas' point of view, otherwise, health professionals must consider the quality of life of the patient over their life span, introducing concepts of palliative care. **Conclusion and implications for the practice:** The above-mentioned concepts changed over time, and knowing them is necessary for critically reflecting on human finitude and rethinking practices that revolve around this process.

Keywords: Terminal Care; Nursing; Ethics; Morals; Decision-making.

RESUMO

Objetivo: Objetivou-se refletir sobre a prática assistencial do cuidado ao paciente com doença terminal sob a ótica da ética e da moral. **Método:** Trata-se de estudo teórico-reflexivo realizado a partir da análise crítica de textos filosóficos sobre ética e moral no contexto do desenvolvimento moral humano e das práticas de saúde. **Resultados:** Na época dos filósofos gregos, a ética se baseava na busca pela felicidade; contudo, com o advento do cristianismo, ela passou a ser vista como um dever. Pela ótica de Kant, a ética e a moral são também um dever, um imperativo categórico, e a questão da manutenção da vida deve ser perseguida, abrindo espaço para a ocorrência de práticas de distanásia. Já para Hans Jonas, o dever dos profissionais de saúde é considerar a qualidade de vida dos pacientes mais do que da quantidade de vida, introduzindo conceitos dos cuidados paliativos. **Conclusão e implicações para a prática:** Tais conceitos se modificaram ao longo da história, sendo necessário conhecê-los, fazer uma reflexão crítica sobre a finitude humana e repensar as condutas nesse processo.

Palavras-chave: Assistência terminal; Enfermagem; Ética; Moral; Tomada de decisão.

RESUMEN

Objetivo: El objetivo fue reflexionar sobre la práctica del cuidado al paciente con enfermedad terminal desde una perspectiva de la ética y la moral. **Método:** Se trata de un estudio teórico-reflexivo, basado en el análisis crítico de textos filosóficos sobre ética y moral en el contexto del desarrollo moral humano y las prácticas de salud. **Resultados:** La ética, en la época de los filósofos griegos, se basaba en la búsqueda de la felicidad, sin embargo, con el advenimiento del cristianismo, ésta pasó a ser vista como un deber. Desde el punto de vista de Kant, la ética y la moral también son un deber, un imperativo categórico y la cuestión del mantenimiento de la vida debe ser perseguida, abriendo espacio para la ocurrencia de prácticas distanásicas. Para Hans Jonas, el deber de los profesionales de la salud es considerar la calidad de vida de los pacientes por encima de la cantidad de vida, introduciendo conceptos de cuidados paliativos. **Conclusión e implicaciones para la práctica:** Tales conceptos han cambiado con la historia, requiriendo conocimiento y reflexión crítica sobre la finitud humana y repensar el comportamiento en este proceso.

Palabras clave: Cuidado Terminal; Enfermería; Ética; Moral; Toma de Decisiones.

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INTRODUCTION

End-of-life and end-of-life care define situations in which people have progressive illnesses and a life expectancy of months or less. During these periods, patients and their families receive physical, emotional, social, and spiritual support and care. The terms may also encompass changes in treatment objectives, such as in the transition of places of care and the level of the technology employed in each case.[1] Taking care of a patient at the end of their life is a complex situation for health professionals, even if the irreversibility of the clinical condition of the disease is known to them. The conflict of different personal values between the professionals who provide assistance and care and those of the patient and their family members raise the discussion of ethical issues.[2]

Technical advances in health practices and academic training predominantly focused on the curative approach have raised doubts about the limits to investing in life support procedures among health professionals. Given this scenario, moral dilemmas become constant, especially when these professionals face the necessity of choosing between artificial maintenance of life or a possible interruption of life support by not offering all possible devices for ensuring the continuation of the death process.[3] Other factors also contribute to the emergence of these dilemmas among health professionals, including little knowledge of terminal care, lack of time and interprofessional relationship, uncertain definition of the patient's condition, and the communicative difficulties between the health team and patient.[4]

The contribution of ethical principles in elucidating moral dilemmas for decision-making in end-of-life care is highlighted, since it permeates the practice of health professionals who deal with the patient in this stage. Therefore, this study aims to present reflections on the care practice of patients with a terminal illness from ethical and moral perspectives.

METHOD

This is a theoretical-reflective study carried out from the critical analysis of philosophical texts on ethics and morals in the context of human moral development and health practices. The considerations were organized through thematic sections from discussions and reflections conducted during the reading of texts that contributed to the emergence of the three sections of this study, namely: i) Ancient moral, modern moral, and health care practices; ii) Kant's categorical imperative and life conservation; iii) Ethics and end-of-life care from the responsibility principle of Hans Jonas: the right to die.

RESULTS AND DISCUSSION

Ancient moral, modern moral, and health care practices

For the discussion presented in this section, Victor Brochard's ideas sustained the approach to the concept of morality. This choice is not an eventuality if we consider that he was a renowned 20th-century French professor and philosopher known for his works on ancient skepticism and Greek philosophy; he left behind an influential contribution to the history of this field of study. Among his works, the author published studies on the thoughts of Greek philosophers (i.e., Plato, Socrates, and Epicurus), and in a specific study, Brochard highlighted the poignant differences between ancient and modern morals, emphasizing the lack of ideas on duties and obligations on the former which are extremely present on the former's conception of moral.[5]

For ancient Greek philosophers, morality as a form of law or commandment had never been conceived — it was seen as an option to be followed or not, rather in the mode of advice than order. Ergo, moral was an ideal to be mimicked or a model to be followed to reach a higher state: happiness in the present life. Conversely, in modern morality, the conjunction of ideas on duty and happiness becomes contradictory, since a good deed done by someone aiming at their own happiness would not be an obligation. Thus, modern morality operates in the form of conscience appeal, while for the Greeks, without the idea of duty, there could be no orders prescribed by the conscience.[5]

The perspective of duty towards morality, which is understood as an obligation to be fulfilled, enables moral dilemmas to be developed and frequently present nowadays. In the health field, if the biotechnological progress has enabled diagnostic and therapeutic methods to be developed, it has also led to the emergence of issues that concern life, death, and human rights in health-related decision-making. The ethical dilemma regarding neonatal end-of-life care for newborns with severe congenital malformations illustrates this issue. The problems first appear during prenatal diagnosis, and the main challenge is to find criteria that allow balancing the protection of the patient's rights, parental expectation who seek to minimize the child's pain, and the non-performance of futile therapeutic measures by the health team.[6]

Similar dilemmas are also present on issues related to organ donation in which questions on the true meaning of life and death arise. Although the lack of brain and brainstem activity endorse the evidence of the patient's death, removing life support makes their family members and health professionals uncomfortable, as the patient still seems to be alive given their continued heartbeats (even if through external therapeutic resources). Hence, health professionals experience ethical conflicts given the difficulty of accepting human finitude and brain death, generating resistance on their part to initiate the proper procedures for testifying to the occurrence.[7]

Within health domains, death is considered a failure to be prevented. The inclusion of a technological arsenal allowed a prolonged postponement of death, which consequently contributes to health professionals persistently seeking to keep their patients alive as long as possible, given that life is understood as sacred.[8] This understanding of morality as a duty was established with the advent of Christianity and its promise of eternal life. This perception ensures moral actions as an act of resignation that would grant greater happiness in another world, and the idea of duty in morality derives essentially from the religious point of view that people have a debt to God.[5]

The intertwinement of modern morals and theology permeates numerous bioethical dilemmas present in the context of terminal patient care. Countless professionals base their decisions on religious beliefs, justifying their actions through faith and personal values, which generates emotional instability and insecurity regarding their conduct.[3] In professional practice, personal values and beliefs influence nursing care and directly interfere with the behavior of these specialists. These characteristics are reflected in the way care is provided to patients and their family members, in addition to causing these professionals to distance themselves and have little involvement in terminal situations.[3,9]

As stated by Brochard, the view on modern morals is surrounded by personal values and beliefs and could be circumvented if completely separated from theology. If so, ideas related to duty and obligation would be eliminated and modern morals would become purely philosophical, scientific, and rational. Therefore, for the author, ideas of morality would not be contradictory since, for reason and science, the supreme end is the good — which is understood as happiness. Both would be only two expressions of the same truth, presented from the perspective of reason and science and the perspective of popular belief. Brochard proposed revising the modern moral understanding without simply going back to the ancient morality concept.[5]

Morality establishes an interdependence and complementary relation with ethics. Both are concepts related to human action and the determining factors which dictate a certain way of behaving. While morality encompasses historical and social norms freely and consciously accepted by individuals to organize interpersonal relations, the concept of ethics is attached to another idea. From a broader point of view, the act of studying moral acts to understand the norms and prohibitions of each system in society and its righteousness in the face of moral order is attributed to the concept of ethics.[10]

When defining ethics, the philosopher Immanuel Kant[11] brings up the term duty that has been so strongly present in the reflection of morality discussed herein. Moreover, the author came up with the categorical imperative concept, as well as other thoughts related to duty which will be briefly presented below, and in which we seek to establish connections with health practices in end-of-life care since Kant's ideas are related to the understanding of human actions.

Kant's categorical imperative and life conservation

In his book Groundwork of the Metaphysics of Morals, Immanuel Kant stated that ethics refers to the internal legislation that makes an action a duty, and the latter is the agent that makes people act according to the law. In other words, the concept of duty alone is already enough to provoke action. Another characteristic pointed out by the author is that ethical legislation cannot be external; thus, divine will and the motivations it generates on people are excluded from the ethical scope.[11]

The idea of an ethical approach based on the understanding of duty was disseminated worldwide from the formulations of Kant's categorical imperatives; these formulations are defined as a conjunction of feelings on common norms shared among all human beings based on values considered absolute.[12] In his categorical imperative concept, Kant reported that certain actions are allowed while others are not because of a moral point of view. These actions, which are morally necessary not for the ends that can be reached through them, but for their own representation, become mandatory and constitute a duty. Ergo, Kant's categorical imperative represents a law that is both practical and moral, in which fulfilling or not these actions would lead to the emergence of sensations categorized as moral feelings. These feelings would arise under the perception of adequacy derived from the conformity or conflict of one's action with moral duty.[11]

A similar concept frequently linked in health care and nursing contexts is that of moral distress; it is defined as the appearance of painful feelings due to actions perceived by the individual as incorrect, either because of their performance or non-performance (characterizing omission). Usually, when performing their care practices, nurses need to question, reflect, and act in defense of the patient's interests, making these professionals assume moral responsibility when acting as a kind of patient advocate. Faced with situations considered inadequate, moral distress arises when nurses do not fulfill their role in a way that is aligned with their principles.[13]

The defense of the patient's rights in the health field integrates the concept of "advocacy" in which professionals seek to claim clients' legally guaranteed rights that are not respected. In nursing practice, the commitment to this practice may help in confronting end-of-life ethical conflicts, in addition to ensuring the autonomy of the professional and patient, as well as their right to access to information and communication. What is more, exercising this practice embodies actions that seek, for example, to use the knowledge about the patient's disease and its treatments to guide and help them in their decision-making process, prioritize the ranking of the real necessities of the patient, and care planning for avoiding conflicts.[14]

Following Kant's ideas on the perceptions of the performance or non-performance of certain actions, one can consider that moral dilemma in the end-of-life care context may relate precisely to the feeling of inadequacy concerning what one considers a duty. Besides the difficulty in dealing with death, a fact that may create feelings of sadness, helplessness, and failure in the professional,[15] especially when they consider death as an occurrence to be prevented, the non-performance of conduct aimed at healing may be perceived by the health specialist as a violation of the duty concerning life.

Regarding life conservation, for Kant, this is the first duty of people toward themselves; the antithesis of this duty would be voluntary death, that is, suicide. The author considers this as not only a duty transgression toward oneself but also a duty transgression toward other people, since when committing suicide, one may abandon social functions (e.g., those of a parent).[11] For the philosopher, life conservation is understood as a duty even if the person acts against their internal will to die, which would essentially define moral behavior. As stated by Kant, the principle of autonomy for one to decide on their own life would be decisive for making this action something aligned with morals, since when deciding to keep living — even when facing extreme suffering — the person would also choose to act according to their duty.[16]

Hence, when understanding the idea of having duty on life conservation from a universal or imperative perspective, as proposed by Kant, one may deal with the emergence of moral dilemmas that permeate end-of-life health care contexts, leading professionals to assume an obstinate position and exaggerate technology used for the artificial maintenance of life at any cost. This professional behavior is named dysthanasia: a concept that happens when measures considered futile to the patient with no expectation of cure are established. This practice may increase the client's pain and suffering. Thus, dysthanasia may be considered an inhuman treatment that disrespects and disregards patient dignity, present when technology use is taken as the main focus of health treatments.[17]

Against moral conflicts and the necessity to make health care choices, negotiation between those involved is essential to allow rights and duties to be fulfilled, in addition to enabling the achievement of benefactions. Ergo, health professionals must become engaged with morally valid care, which is also sustained by ethical principles that both respect and value any other involved in the dynamic (e.g., patients, their family members, and multidisciplinary team), allowing their subjectivities and values to be exposed and considered in decision-making processes.[18]

In this perspective, the nursing code of ethics contains information that views respect for human rights as inherent to the exercise of the profession. This is because nurses partake in health care at all stages of life and are also responsible for the health promotion and restoration, illness and injury prevention, and suffering relief while considering human beings' completeness and respecting the will of the patient or their legal representative.[19] The professional urge to do what they believe to be the most certain and adequate procedure toward the patient is understood as a compassionate characteristic, one of the components of moral sensibility, and a concept that is related to moral reason, the ability to apply principles against ethical problems, and direct decision-making based on the best benefits of patients in nursing care. Besides this benevolent motivation, there are other components related to nurses' moral sensibility, including moral conscience (i.e., to act following the ethical code) and spontaneous moral perception (i.e., the ability to recognize ethical problems).[20]

In addition to the above-mentioned elements, critical and clinical reasoning, professional autonomy, effective communication, leadership, ethical education, dialogue, and proper relationships with the team are relevant attributes of moral sensibility to direct decision-making processes. At the same time, professionals should consider the best benefits for patients when facing ethical conflicts present in nursing care.[20] In contrast to the idea of morality and ethics as prescribers of actions that have an end in themselves, that is, that are carried out because of a sense of duty, one might also consider the emergence of the ethics of responsibility — a concept by the philosopher Hans Jonas.[21] This concept brings up the necessity of reflecting on the consequences of actions that are performed in the health field, as well as the relevance of defending the end-of-life dignity of the patient, ideas that are presented below.

Ethics and end-of-life care from the responsibility principle of Hans Jonas: the right to die

When reflecting on the concept of ethics of responsibility, the philosopher Hans Jonas is concerned with the advances of science and its impacts on human life's permanence on Earth. The author defends that human action must be based both on conscious choices about oneself and the implications these actions may cause on other people and future generations. For him, liberation achieved through technological advances has limits and its proper application is only possible when based on responsibility. He also emphasized that one pivotal point that differentiates human beings from technology is the capability of providing care.[21]

In contrast to traditional ethics — based only on "here and now" and which cannot control the risky effects of technological usage — ethics of responsibility is rooted in ontological elements, an adequate alternative for avoiding catastrophic situations and encompassing duty with nature and with those who do not yet exist. Additionally, this assumption also defends that against scientific uncertainty, caution, responsibility, and prudence are required. One of the key points of Jonas' concept lies in drawing attention to the fact that technologies may be used either for good or evil intents and that people need to make good use of them even when dealing with negative consequences of their use.[22]

Concerning end-of-life care, Hans Jonas stated that excessive life prolongation and consequent death postponement is a professional behavior that goes against the responsibility toward humans and may even be in disagreement with the will of the patient who is subjected to a situation that causes suffering due to to the overuse of technologies.[21] Thus, it is possible to state that the philosopher is openly against dysthanasia. This perspective may be strengthened in health institutions and societies that tend to overestimate technology and prioritize healing over caring, where death threatens the main function of hospitals: providing healing.[23]

Establishing discussions between people involved in the life terminality process is fundamental for fairer decisions to be taken, aiming at not performing futile therapies. As for clinical conditions considered irreversible, it is crucial to establish these dialogues that may clarify family members' doubts and demonstrate possible treatment alternatives that may offer the patient comfort and mitigate suffering against the condition. Actions that aim to help the patient overcome feelings of dependence should also be taken into consideration, as it contributes to respecting their autonomy.[24]

Contrary to dysthanasia practices lies the concept of orthothanasia: a process in which life ends naturally without adopting any extraordinary interventions for postponing the patient's imminent death, a more humanized procedure. This process is recognized by the Brazilian legal power and is associated with the necessity of effective care, such as pain control, in addition to the improvement of public policies and supplementary health surveillance.[25] Nonetheless, the occurrence of dysthanasia in care practice is still common, even with the knowledge of the importance of end-of-life care based on the principles of orthothanasia.[26]

Still drawing reflections on the end-of-life, the philosopher Hans Jonas shed more light on the matter by addressing one's right to die. For him, this right is conceived when one finds oneself in a situation where living is an imposed obligation and death is under the control of another human being. These people would be critically ill and exposed passively to technologies that postpone their death, which in their understanding, lead to the extent of suffering and precarious survival. This would cast doubt on to what extent their rights are being preserved.[21] The philosopher's perception is based on the principles of palliative care, among which he seeks neither to postpone nor to accelerate death, but to offer the patient who faces a disease that threatens their life a proper quality of life and to ensure their dignity.[27]

Two examples proposed by Hans Jonas illustrate his position. Consider two patients: one conscious, in a terminal state of advanced cancer, the other unconscious, in an irreversible coma. For the patient to exercise their right to die in the first case, they must first be fully informed of their condition to decide freely and autonomously what to do with their remaining time of existence. Along these lines, the right to die becomes inseparable from the right to autonomy. Therefore, the health professional must allow the patient to make an informed decision by not omitting any truth nor nullifying their right.[21]

The patient's autonomy in the above situations is one of the fundamental principles of health ethics, imposing on professionals and family members respect for the decision made by the client, including on aspects of life support. Likewise, communication among all people involved in this process must occur openly and honestly, allowing the free expression of patient's choice (even if they choose not to engage in making decisions about end-of-life care), therefore contributing to the care based on the valorization of their needs and singularities.[28]

As for the second example proposed by Jonas, that is, the unconscious patient case who is unable to autonomously choose their treatment, the philosopher explained that there would no longer be a right to die in the literary sense since, in order to have a right, there must be a subject who requests it. Nevertheless, the author suggested that a statement of intent previously written by the individual would serve as moral support on this occasion since it would indicate the patient's acceptance, including in the legal sphere. This idea is similar to the concept of advance directives (AD), a written genre used to manifest personal preferences on health care that only come into force when the patient can no longer express their will.[29]

The AD is recognized as a partially facilitating instrument for resolving indecisions on conduct and conflicts that revolve around life terminality. Furthermore, it stimulates deepened dialogue about the patient's wills and wishes. It preferably should not be written during an end-of-life context as there may be an emotional overload at this time.[30] In Brazil, there is no legislation regulating AD — just a few resolutions published by some health professional categories. In the nursing field, Resolution No. 564/2017 mentions the issue in its second chapter when determining that the nursing professional must respect the patient's AD when they cannot express their wishes. Additionally, the resolution also declares that nurses must respect the patient's right and their legal representative to exercise their autonomy in decision-making processes concerning health and other aspects, considering ethical and legal principles.[19]

In any case, the author believed that in irreversible cases in which the patient is kept alive only at the cost of artificial and technological devices, the removal of life support by professionals is not only a right or an obligation, but also a moral act. Thus, allowing the death of a person kept alive by artificial means is to listen to reason and humanity by putting an end to the degradation of a forced existence. The philosopher perceived that the role of health professionals should be that of "guardians of human rights." However, such a posture requires both a metaphysical look toward life and death and also the end of the understanding of the right to die as sustained by the social justice principle.[21]

For Hans Jonas, thus, it is necessary to rethink measures undertaken in the process of end-of-life patient care, keeping in mind the principle of responsibility as an ethics of care and the thought that death, just as birth, is a natural occurrence.[21] In this way, one can understand health care based on the principle of responsibility, which encourages professionals to reflect on a more balanced use of life support technologies, therefore avoiding its negative impact on the client's dignity as much as possible.

CONCLUSIONS AND IMPLICATIONS FOR THE PRACTICE

After reading the philosophers presented herein, one can perceive that the understanding of the moral concept is presented differently in distinct moments of the history of humanity. Nonetheless, whether based on a moral that receives religious influence or a moral that is taken as a happiness ideal, health care professional practice is directly impacted by these two positions, which determine the decision-making processes when caring for an end-of-life patient.

Although free from theological influences, Kantian morality considers life conservation as a primary duty, and such an attitude would characterize this action as something moral. From this point of view, the categorical imperative enables the appearance of dysthanasia practices since the moral feeling toward the end of life would be to maintain it. As a form of disruption concerning these concepts, the responsibility principle of the philosopher Hans Jones and the "right to die" idea merge into the foundations of palliative care when considering that quality of life is as valuable as life itself, even more than life span. The patient in the end-of-life stage is introduced to concepts of autonomy on choices that involve their values and preferences, including an outline of what their advance directives would be.

Hence, this study allows the reflection on practices of health professionals toward patients in the end-of-life state, enabling the conclusion that these processes are influenced and surrounded by conceptions of morals and ethics discussed here. Knowledge regarding the philosophical perspectives discussed herein facilitates critical reflections on human finitude and the possibility of rethinking measures surrounding this process, resulting in more ethical and autonomous decision-making that value people's dignity and mitigates the suffering in life terminality.

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