The Dying Process across Human Life Cycle: Ethical Considerations on Terminal Care

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Abstract

Dying is an event that affects human development throughout the life cycle—impacting individuals, communities, and society. Providing terminal care may mitigate the suffering of patients and families. Notwithstanding, it poses challenges concerning patients' decision-making and autonomy, in regard to communicating bad news, resuscitation orders, and voluntary termination of life. This study seeks to discuss ethical issues underlying terminal care, showing how the problem of patients' decision-making and autonomy can be addressed at the end of life. It distinguishes the notion of worthy death, which could ground ethical decisions for health attention across different developmental stages.

Keywords

Terminal Care, Decision-Making, Autonomy, Bioethics, Developmental Psychology

1. The Dying Process

The notion of "death" can be defined as the complete cessation of vital functions, while the "dying process" refers to the ultimate and progressive loss of such functioning [1]. The dying process is an important event in human development, and we can technically and ethically distinguish a good death from a bad death. A good death can be understood (with respect to patients, families, and caregivers), as one liberated from avoidable and unnecessary suffering, and which had occurred in accordance with cultural, ethical, and clinical standards [1].

In the medical and legal spheres, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research [2], working with the American Medical Association and the National Conference of

Commissioners on Uniform State Laws, has established the following medical criteria for death: irretrievable cessation of circulatory and respiratory functions, or irretrievable cessation of all brain functions, including the brain stem.

In Brazil, the Federal Council of Medicine, through Resolution No. 2173 of 2017, has established criteria for the definition of brain death. Brain death must be determined among all patients who have a non-perceptive coma, absence of supraspinal reactivity, and persistent apnoea. Patients must also clinically present brain injury of a known and irreversible cause, absence of treatable factors that would confuse the diagnosis, treatment and observation in the hospital for a minimum of six hours, a body temperature over 35˚C, and arterial saturation according to criteria established by the resolution; parameters differ for children [3].

Considering the behavioural aspects of the dying process, Kübler-Ross [4] has proposed a system classifying individuals' responses regarding the experiences of loss and death. It should be highlighted that the following sequence of behaviours is not invariable or applicable to everyone; however, five stages are commonly presented and can occur in different orders and intensities. The first stage is the one for shock and denial. These are reactions people may present initially, when told they are dying or could suffer an important loss. As a result, people usually do not accept the diagnosis; what can be problematic since such denial can influence patient initiation and adherence to treatments [4].

In the second stage [4], people react with anger, irritation, presenting wrath when considering the fact of getting ill. Such angriness may be directed to God, destiny, or close people, as parents, sons/daughters, relatives, as well as a friend; people even blame themselves. They may also transfer their anger to the health professionals who assist them, blaming the staff for their illness. Professional who deals with such individuals must not perceive the expression of anger as personal attack, and be aware that these reactions may be one of the few resources available to patients to cope with a situation felt as out of their control [4].

As for the third stage, a common behaviour is the attempt of patients to negotiate and bargain with professional staff, their family, or friends, or even with God. With such attempts, people hope they could achieve a cure. To receive this reward, people usually make promises, engage in prosocial behaviour, donate to charity, or perform religious rituals. Behind the bargain, there is a belief that if one is good, not questioning, collaborative, the doctor will dedicate themselves harder to treat the patient [4].

In the fourth stage (depression), one can exhibit signs of clinical depression (*i.e.* psychomotor slowing, sleep disorders, hopelessness, and possibly suicidal ideation) [4]. It is must be highlighted that it is normal to a person experience sadness at the prospect of her/his death or an important loss. But if a depressive disorder is established, people should receive adequate clinical treatment. A depressive disorder impairs treatment adherence and compliance to medical instructions, which will ultimately influence one's life expectancy [4]. The accep-

tance stage (fifth stage) is defined by Kübler-Ross as patient's realisation of the inevitability of death and loss, and the universality of such experience. The range of feeling and reactions are diverse in this stage. People may be neutral in accepting their finitude, while others may behave with euphory. In ideal circumstances, patients can face these feelings and cope maturely with uncertainties brought by death [4].

For those who experience the death of a beloved person, a natural process known as mourning may be triggered. Grief consists of a set of feelings, thoughts, and behaviours that express, in a cultural context, an individual's subjective experience regarding loss. This experience has characteristics varying for intensity, duration, and the different stages of human development.

Although mourning is an expected and natural response to death, certain behavioural responses may require mental health assistance. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) hypothesizes the existence of a "Persistent Complex Bereavement Disorder" [5]. This hypothetical disorder is notably classified by the DSM-5 in a chapter entitled "Conditions for Further Study". The manual acknowledges, however, that studies have not found enough evidence to guarantee its inclusion as an official mental disorder diagnosis, thus requiring its further investigation.

The disorder's main characteristics are as follows. It is required that at least 12 months (six months in children) must have passed since the death of someone with whom the mourner had a close relationship (this interval discriminates between normal and persistent mourning) [5]. The condition involves symptoms such as 1) marked difficulty in accepting that the individual has died; 2) anger at the loss; 3) desire to die to be with the deceased; 4) feelings of isolation; 5) belief that life is meaningless without the deceased; and 6) experiences of a diminished sense of identity, among other symptoms. Finally, the nature or the severity of mourning must be beyond the norms expected for the relevant cultural context, religious group, or stage of development [5].

DSM-5 furthermore underlines that "persistent complex bereavement disorder is associated with deficits in work and social functioning, and with behaviours harmful to the health, such as increased use of tobacco and alcohol". Not only, but "it is also associated with a marked increase in the risks of serious medical conditions, including heart disease, hypertension, cancer, immune deficiency, and reduced quality of life" [5].

2. Dying Process across Life Cycle

The characteristics specific to each period of the human life cycle influence the attitudes and reactions of individuals regarding death as well as the attitudes of their family members and peers.

2.1. Dying in Children

In preschool children, death is commonly seen as a temporary, reversible ab-

sence—as if one were leaving to another place or felt deeply asleep [6]. However, according to neo-Piagetian authors, from the age of five, children can understand death as a final, irreversible reality [7]. Children in this life stage can also understand other aspects of death, such as its universality ("all living beings die"), its inevitability, and the non-functionality of a dead person ("functionality ceases with death").

This knowledge results from the cognitive changes that a child goes through during this life stage. However, this transformation is gradual. For example, studies have indicated that not all children aged five to 11 understand that an individual's mental states cease with death [8]. Children can better understand death if they are instructed in this regard, and if the topic is addressed organically. From the point of view of their attitudes, children, as well as adolescents and adults, do not perceive death without ambivalence.

Children may have different reactions to the possibility of their own death or that of a loved one, such as denial and avoidance, social withdrawal, regressed behaviours (e.g. enuresis or increased dependence), somatic reactions (e.g. loss of speech or appetite, disturbed sleep, constipation, or fatigue), school difficulties (e.g. deterioration in school performance or resistance to going to school), and mood changes (e.g. agitation or apathy) [6].

The anguish of being separated from caregivers is a frequent cause of anxiety for children and can manifest as nightmares or in games. Children in the terminal condition of their health may be aware of their situation. If they show the desire to talk about such situation, it should be done. Having a honest and sincere conversion may be helpful in addressing children's concerns, providing information once requested, and respecting children developmental limits [6].

The grieving reactions of children, adolescents, and adults are influenced by their level of development and the concepts of death they have. Children may exhibit minimal mourning at the time of death but experience a more intense effect of the loss afterwards. Disruptive behaviours may also be exhibited [6]. Children may feel responsible for the death of a person close to them due to some previous behaviour of theirs or because they had fantasised in a certain way that the person would die.

It is common for children to elaborate their anxiety regarding death, through games. Games materialize fantasies and fears, offering children the possibility to develop resources of coping with sorrow and psychological trauma. However, children must be frankly, and timely, informed of the irreversibility of death. They should be encouraged to express their feelings and have their question addressed. Attending the funeral and participating in rituals can be beneficial in coping with loss [5].

2.2. Dying in Adolescents

From a cognitive point of view, teenagers are capable of logical and abstract operations. They are able to understand that death is inevitable and final. But given

the developmental characteristics of adolescents, they may not accept that death may effectively occur to them. From a neuroanatomical point of view, the adolescent brain is immature; neural circuits responsible for judging and inhibiting impulse control have not yet been fully developed [9], and this contributes to risk behaviours, such as harmful substance use, unprotected sex, violence, and dangerous driving, commonly observed in this age developmental stage.

Even though for many adolescents death is a distant event, when confronted with this reality, they may present different reactions, such as alternating emotional states of despair, anger, joy, and insensitivity; somatic complaints; compulsive and risky behaviours; and school problems (e.g. dropping out of school). Adolescents who are dying may also have common fears, which include loss of control, being imperfect, and being different [6].

Concerns about body image (for example, hair loss, or changes in the body structure) can lead to avoidance of treatments, and the potential for isolation is significant. Adolescents also have a wide variety of expressions of grief, from behaviour problems (e.g. violence or compulsive sub-stance/sexual behaviours), somatic symptoms, mood lability, and even an apparent state of immovability [6]. Adolescents must not be put aside to decisions regarding their own death.

2.3. Dying in Adults and the Elderly

Young adults who have started a professional career, gotten married, or have just had children may feel frustrated and angry at the possibility of death itself. In contrast, middle-aged and elderly adults may be more prepared for the experience of death than young adults.

Reactions commonly presented by adults in the face of death include sadness at being separated from loved ones, home, and work; fear of becoming a burden to others; concerns about their dependents' future; and fear of pain or other worsening symptoms. Communication concerns arise from distress, thus requiring the promotion of trustful and comprehensive bonds between these individuals and their caregivers [5].

In the context of mourning in adulthood, an experience that deserves mention is the loss of children. The death of a child is a life-changing experience. Sudden deaths are particularly problematic because they are unexpected—with no anticipation and prior elaboration of the loss—as in terminal illnesses. Parents may blame themselves or accuse each other for the loss, resulting in marital difficulties. Seniors, in general, may accept more easily their finitude [6]. Their main fears include experiencing a prolonged and painful death, a prolonged vegetative state, isolation, and loss of dignity.

The elderly usually suffer losses in a higher frequency, given the cumulation of events across life cycle. Such losses may have an important impact on these individuals, which goes beyond the affective and relational domains. Disabled elderly people who lost a spouse may, with that, also have lost a mate who offered help for daily functions, rendering him/her vulnerable in face of life's adversities [6].

On the other hand, when it comes to their own death, the advanced age and experience may help elderly patients perceive death with greater tranquillity and a sense of accomplishment.

As Erikson [10] has pointed out, when in the last stages of their lives, the elderly increasingly reflect on their past. Self-integrity, acquired during human development, may allow them to better cope with illness and death, whereas those who have not developed this integrity may face death with despair and live it as an experience of failure.

3. Terminal Care and Ethical Implications

Given the universal and irreversible nature of death, we must ask ourselves what kind of healthcare should be provided to individuals with terminal conditions. Adequate care can mitigate the suffering that accompanies dying, providing individuals with a good death (*i.e.* a death with dignity and endowed with meaning). Terminal care can be of a curative or palliative nature.

While curative care aims to reverse a clinical condition, thereby restoring vital functions, palliative care aims to relieve symptoms and discomfort caused by a critical health condition, even if its reversal is not possible. Ideally, healthcare professionals should strive to prolong life and undertake treatment efforts; while at the same time, they must accept death as an intrinsic component of life, which defines its existential meaning [11].

Palliative care is often associated with analgesic drug administration for pain management, but other measures can be used or carried out, such as providing a room with privacy and comfort to patients (given that intensive care units may be stressful), and allowing family members to be in the presence of the patient. The use of palliative methods also includes discontinuing invasive interventions (e.g. equipment for access, measurement, and maintenance of functions) to provide greater comfort for the patient.

Terminal care raises ethical questions about the legitimacy of interventions related to dying. If, on the one hand, technological advances have enabled greater control over vital processes, on the other hand, we are faced with problems such as the patient's autonomy and his or her decision-making power regarding his or her own death. Some of the main problems that emerge in this regard are do-not-resuscitate orders and refusal of treatments, choice of where to die, active interruption of life, the right to information, and transparent communication.

Do-not-resuscitate orders seek to prevent professionals from performing procedures such as cardiopulmonary resuscitation, or other interventions considered unnecessary and invasive. In Brazil, Resolution No. 1995/12 of the Federal Council of Medicine [12] established criteria to allow an adult and an aware person to define, together with his or her doctor, the limits of procedures in the terminal stage (decisions that will be indicated in a living will). For patients who have not left directives or are legally incapacitated, hospital ethics committees can assist with these decisions.

A second issue involving a patient's autonomy concerns the choice of where to die. Depending on the patient's will and the nature of his or her illness, dying at home may be an option. A home care team can provide therapeutic support and assess the needed adjustments to the patient's home (e.g. modifications to furniture and the installation of assistive devices). Family participation in this process is essential; it must be included in decision-making and its responsibilities must be discussed with the patient.

A third issue related to autonomy concerns the active interruption of life via, for example, euthanasia. From the Greek, euthanasia means "good death" and designates the act of actively causing the death of another person. In general, it is used to relieve suffering, maintain dignity, and shorten the process of death when it is inevitable.

Those who oppose euthanasia, firstly, argue that euthanasia, even if desired, continues to be "killing" and therefore should never be sanctioned. Secondly, those patients who desire such termination may be, otherwise, suffering from depression. Once this depression is treated and patients are offered clinical and social support, they may change their opinion about their desire to die. Institutions that oppose euthanasia include the American Psychiatric Association [13], the American Medical Association [14], and the British Medical Association [15]. These institutions claim that this practice contravenes ethical principles, such as beneficence and non-maleficence, and if put into effect, it would especially affect more vulnerable population groups.

In turn, positions favourable to euthanasia, espoused by authors like Savulescu and Schuklenk [16], include 1) legal arguments (e.g. the individual has the right to die, or it is not up to the state to interfere in the dying process), 2) practical arguments (e.g. it is possible to release euthanasia and regulate this act, thereby preventing it from being indiscriminately practised), and 3) philosophical arguments (e.g. the utilitarian principle of maximising well-being).

In Brazil, euthanasia remains illegal and can, at best, be classified in the penal code under the category of "privileged homicide"—that is, a crime committed under strong emotion, compassion, or a reason of social or moral relevance, which could reduce the penalty of those who committed it [17]. It should be noted that euthanasia differs from "assisted suicide", a practice in which a doctor, or another individual, helps someone (*i.e.* by providing them with means) cause their own death.

Finally, an important issue regarding a terminal patient's autonomy and decision-making power concerns transparent communication and the way information regarding death is transmitted to him or her and his or her family. Conversations should take place in an appropriate, private, and time-available space. The professional must explain the situation to the patient and family—with a clear and simple language. The amount of information and when it is given must be based on the needs and resources of each patient. One must know that prognosis regarding life expectancy may be (and not rarely is) inaccurate. In addition, the

health professional needs to make it clear to his patient that he/she will receive all the required support, as long as necessary [18].

Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

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