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UPDATE

Spinozian power: resistance to control over death

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Abstract

This study discusses the issue of end-of-life decision-making, considering Foucault's ideas of a technology for managing life that exerts power over bodies (biopower) by a disciplinary system, and politics that prescribes ways of living (biopolitics), and Spinoza's concept of the body and affects (*affectus*). We conclude that, despite the numerous obstacles to autonomous decision-making by patients, individuals have an absolute power that favors their protagonism. However, their small gestures are often invisible to health professionals.

Keywords: Bioethics. Decision making. Terminal care. Personal autonomy.

Resumo

Potência spinoziana: resistência ao controle sobre o modo de morrer

Este ensaio discute a tomada de decisão no fim da vida considerando o pensamento de Foucault e Spinoza. São tomados como referência dois pressupostos. O primeiro é o reconhecimento de tecnologia de gestão da vida que busca exercer poder sobre os corpos (biopoder) por meio de sistema disciplinar que prescreve modos de viver (biopolítica). O segundo pressuposto considera o conceito de corpo e a teoria dos afetos de Spinoza. Pôde-se concluir que, apesar dos obstáculos à tomada de decisão autônoma por parte dos pacientes, os indivíduos têm potência absoluta que lhes dá protagonismo. Seus pequenos gestos, no entanto, muitas vezes são invisíveis ao olhar dos profissionais de saúde.

Palavras-chave: Bioética. Tomada de decisões. Assistência terminal. Autonomia pessoal.

Resumen

Potencia spinoziana: resistencia al control sobre el modo de morir

Este ensayo analiza la toma de decisiones al final de la vida considerando el pensamiento de Foucault y de Spinoza. Se toman como referencia dos supuestos. El primero es el reconocimiento de la tecnología de gestión de la vida que busca ejercer poder sobre los cuerpos (biopoder) a través de un sistema disciplinario que prescribe formas de vida (biopolítica). El segundo supuesto considera el concepto de cuerpo de Spinoza y la teoría de los afectos. Se pudo concluir que, a pesar de los obstáculos para la toma de decisiones autónoma por parte de los pacientes, los individuos tienen un poder absoluto que les otorga protagonismo. Sin embargo, sus pequeños gestos suelen ser invisibles para los profesionales de la salud.

Palabras clave: Bioética. Toma de decisiones. Cuidado terminal. Autonomía personal.

This article aims to discuss end-of-life decision-making based on two assumptions. The first is the existence of a technology for managing life – techniques for governing populations that seek to exercise power over bodies (biopower) via disciplinary systems and political strategies that prescribe ways of living, that is, biopolitics. This debate helps to reflect on how end-of-life is associated with the issue of government and power¹.

The second assumption comes from Spinoza², according to which, instead of inertly following nature's order, human beings have absolute power over their actions, being self-determined. Thus, in the context of health, the decision, often attributed to the professional, especially the physician, must be made by the patient, who should be in control at the end of their life.

This activism about one's life is ignored by health professionals who focus only on scientific possibilities of intervening on bodies. However, what we often observe is an intense activity of individuals who are no longer attributed full life, but who in many cases preserve the ability to choose their end. All bodies have power and are capable of affecting and being affected. The body's activity, its vitality, is measured by this ability to affect, increasing or reducing its possibility to act³.

These two assumptions dialogue with each other, articulating the society and government dimensions of the living with the micropolitics of affections, which presupposes high power of action and resistance to control mechanisms. Based on the idea that life and death are shaped by the social, environmental context and ways of life of a given time, it is important to realize that the rapid urbanization since the 1970s, which resulted in the migration of the rural population to the cities, transformed Brazil's demographic profile⁴.

As a result of the technical-scientific advances that accompanied this process, the birth rate dropped while life expectancy at birth increased⁴. Urbanization also changed the population's food and physical activity profile, increasing the prevalence of chronic-degenerative diseases. These factors, associated with new techniques of life maintenance and extension, prolonged the dying process, intensifying the patient's suffering^{4,5}.

Therefore, there is growing concern about issues related to the end-of-life, including care and prevention of suffering. Among these issues is discussing treatment with patients, family members and health professionals. Considering the

treatment the person would like to be submitted to, encouraging shared decision-making, is part of a good clinical practice⁶.

Situations in which professionals decide for the patients, it is not only the prognosis that influences the judgment, but also personal values and beliefs. However, the opinion of the medical team does not always coincide with the values of the patients and their family members. Sprung and collaborators⁷ showed that, while professionals value "quality of life" more, patients ascribe more value to life itself, despite their well-being⁶⁻⁹.

To avoid mistaken decisions, Schwarz⁸ suggests that decision-making be shared, both with team members and with patients and their families. For the author, discussing and deliberating together, besides contemplating the patient's best interests, favor moral reflection. However, in practice there are no equal rights in communication since the parties have unequal access to the power to decide¹⁰.

For Rego and Palácios, *death* [usually] is *determined by the physician*¹¹. However, the question of when and how to die should not be seen as the right of the professional, but of the patient. Before being medical, the problem concerns people's autonomy and the right to dignified death¹². Considering the importance and complexity of the topic, this essay discusses how the decision-making process occurs at the end of life, given the various mechanisms involved.

Devices in the end-of-life

Hippocrates, the "father of medicine," advocated high moral standards for the profession, defining as goals for medical practice to relieve the patient's suffering, reduce the aggressiveness of the disease and not expose the patient to treatments when no more benefit is possible, according to Bitencourt and collaborators¹³. The authors also stated that, for the philosopher, medicine should not treat those who were overcome by the disease, admitting impotence in cases where there is no prospect of cure.

The evolution of science, technology and medicines has brought benefits to the treatment of critically ill patients, but also the possibility of postponing death indefinitely. The indiscriminate use of artificial resources prolonged life, but at any cost, maintaining vital functions without the slightest respect for the patient's human dignity¹⁴.

According to Villas-Bôas¹⁵, dysthanasia occurs when treatment no longer achieves its objectives and therapeutic resources are used to prolong the life of patients with incurable diseases without real chances of success and significant benefits to prognosis and quality of life. Suffering then becomes greater than the benefit, and in such cases, it is inhumane to persist with treatments. If it happens in spite of the patient's will, dysthanasia not only eliminates comfort, but also violates human dignity^{9,15}.

The difficulty in dealing with death, felt by both patients and family members and health professionals, has favored this practice. Although no legal duty to impose such conduct exists, teams continue to invest in the treatment of terminally ill patients for fear of legal constraints, seeking to defend themselves against accusations of malpractice¹⁶⁻¹⁸. But the fact that resources exist does not imply that they should be used in all patients, at all times and under any circumstances, because not everything that is technically possible is ethically correct^{15,19}.

Until the 20th century, death was considered a natural process, the common destiny of all living beings. In the period preceding the technification of medicine, people died at home, usually surrounded by family, friends and acquaintances and accompanied by a religious leader responsible for conducting the mortuary rituals. This relatively simple and peaceful way of facing the end of life was forgotten as advances in medicine became present. Faced with increasingly effective drugs, tests, clinical and surgical procedures, death began to be considered appalling, a transgression to life. In the second half of the 20th century, death becomes definitely inconvenient; it becomes taboo. From then on one no longer dies at home, but at the hospital²⁰.

Other factors that motivate dysthanasia are the mistaken idea that it is a form of care and the reference to the biomedical model, which emphasizes health as a competent intervention on the depository body of the morbid process. The fascination with technological advances in the equipment industry – fueled by marketing strategies, the media and intervening microstructures in the workplace – intensifies the perception that death is an obstacle that can (and should) be overcome by science and medicine²¹. This reflects on the training of professionals, who learn a lot about cutting-edge technology, about how to save lives, but little about death. In other words, health professionals are not prepared to deal with the end of life²².

Given this context, orthothanasia arises to contemplate dying well, using care resources for patients with incurable diseases, as to provide conditions for dignified, peaceful death, focusing particularly on the affective dimension at the time of dying. Orthothanasia is defended whenever recovery is no longer possible and the decision about treatment can be made by the patient in a lucid and responsible manner. It values the individual's autonomy, respecting their beliefs, interests and personal needs^{9,15,20}, preventing procedures from being used indiscriminately. Its goal is to provide comfort to the patient. Based on bioethical principles, this approach is not considered a crime, as it comprises the prescription or not of a given treatment, without shortening or prolonging the patient's life^{15,23}.

In addition, the World Health Organization (WHO) recommends palliative care in cases of life-threatening illnesses. According to Oliveira, the WHO defines this type of care as an *approach that promotes quality of life for patients and their families (...) via the prevention and relief of suffering. It requires early identification, assessment and impeccable treatment of pain and other physical, psychosocial and spiritual problems*²⁴. The goal of palliative care is not to cure or control the disease, but to promote patient comfort without interfering in the progression of the disease. Its purpose is to obtain a better quality of life, controlling pain and relieving symptoms, thus guaranteeing the dignity of the person and humanizing the dying process^{15,25}.

Euthanasia, on the other hand, is understood as anticipating death, at the patient's will, as a humanitarian alternative to interrupt unbearable suffering. Criticism to this approach is based on the principle of sacredness, according to which life is bestowed by divinity, and therefore is always worth living. According to this conception, despite the suffering, the patient's life cannot be interrupted, even if that is their own expressed will^{5,26}.

There is also the fear of death, qualified as evil, which leads to the primary objection against the active and voluntary euthanasia of the other. From the health professional's perspective, especially the physician, death is treated as an error since their undergraduate course, as an opponent to be fought and defeated. Thus, the life-death dialectic is always present: either the physician gets it right or the patient dies^{26,27}.

Voices in favor of euthanasia, in turn, based on the principle of autonomy, defend peoples' freedom

of choice, allowing them to define their life's outcome, even if their decision is to end suffering through death itself²⁶. Only the person himself is best suited to decide on the end of their life. It seems consistent to respect their desire to cease unbearable and undesirable suffering or, on the contrary, to continue suffering, if that is their will^{12,26}.

Deciding on the end of life is the moral right of each individual, and as such must be respected by society and protected by the Law. Although trained to save lives, physicians must recognize the patient's values, understanding that their technical knowledge should not override the individual's decision about their own existence. Moreover, the principle of autonomy places patients as the only moral authority over their body. At first, no one has the right to decide for them or limit their decision^{12,28}.

Rational beings make free and therefore autonomous choices. Individuals, as the minimum unit of morals, chooses for themselves what they consider fundamental, defining how to live their life and what constitutes a dignified life – and this must be extrapolated to death. Thus, it is considered immoral to prevent decisions about end-of-life made by individuals capable of determining their own end¹². Paternalistic attitudes, often based on the principle of sacredness, deny what one chooses for themselves.

This interference violates autonomy, imposing a condition of immaturity that denies the subject's authorship over their own life. The individual, who has made choices about all fundamental aspects of their existence, cannot be denied the right to decide on their end. What should be sacred is the respect for the person, the patient's autonomy and their dignity.

Thus, the key issue in care at the end-of-life is the informed decision²⁹. Health professionals must communicate to the patient all information on their condition without any value judgment, the decision being entirely the responsibility of the patient or their legal representative. It is not a question of transferring responsibility to the patient, but of providing the necessary technical information, making sure that they are understood and respecting the conscious and autonomous choice.

The power of the State and decision-making at the end of life

From the 17th century to the first half of the 18th century, techniques of power were essentially

centered on the body, through an individualizing disciplinary technology. In the second half of the 18th century, a new technology of power emerged, which aimed to reach not the man-body, but the man-species. As Foucault³ describes, we move from "anatomo-politics" to "biopolitics".

At this moment, the objects of knowledge emerge, bringing information on birth, mortality and longevity. The statistical measurement of these phenomena generates the first demographics, which evidence the first targets of biopolitics, defining the field of intervention. This new policy employs different mechanisms, regulatory rather than disciplinary, but which control behavior in the same way, aiming to maintain the overall balance¹.

The sovereign power to take life or let live gives way to biopower, which controls accidents, adversities and eventualities to provide "more life" and thus maintain the workforce. Increasingly being the right to live, this power disqualifies death and its ceremonies, making them shameful³. It takes on a new field, which consists not only of organizing and fostering life, but of making live even beyond "death".

Biopower can make people live even when, biologically, they should be dying, enabling the practice of dysthanasia, which is the intersection between sovereignty over death and the regulation of life³. Likewise, the State has control over who should live by prohibiting the practice of euthanasia to those who have decided to do so autonomously. In short, biopower begins to configure governmentality, transforming life into its object.

Doctor-patient relationship and the power-knowledge

In the doctor-patient relationship, the physician supposedly holds scientific knowledge, and therefore always occupies a hierarchically superior position in the decision-making about health, ways of life, therapeutic projects and moment of death. Thus, the doctor would hold the power to define what is right, what habits should be followed, and which are the best behaviors. This situation, by itself, already submits the patient to an unequal and asymmetric relationship^{1,3}.

This perspective has been built since the 17th and 18th centuries, when medicine was classificatory, focused on the nosographic model. The physician's superficial gaze analyzed and categorized the disease. At the end of the 18th century, this type of practice gave way to clinical medicine, due to

changes in the organization of medical knowledge. Then new “codes of knowledge” emerged, based on perception. While classical medicine catalogued diseases in an attempt to illustrate theory, clinical medicine finds its object in sensorial knowledge³⁰.

In the 19th century the “anatomy-clinic” was born, according to Foucault’s³⁰ nomenclature, from the conjunction of clinical practice with pathological anatomy. A new domain, that of anatomy, is now explored. The proposal is to locate the disease in the affected organ and, thus, define the ailing body as the scope of medical perception. Along with medicine, as a practice and science, the hospital domain was also reorganized, functioning now as a space for medical practice and construction of knowledge. Anatomoclinical medicine delivers the lifeless individual to knowledge, as an object to be unveiled by the autopsy.

Current care focuses on the disease and prescriptive treatment, simplifying and stiffening medical work. The most relational technologies, which considered the individual integrally, resulting from the health-disease process and influenced by socio-environmental factors, started losing space to the excessive use of instrumental technologies^{31,32}.

Merhy³² describes the physician’s performance from three technological tools. The first, linked to the hands, refers to equipment and instruments (hard technologies). The second, related to the head, encompasses expertise, knowledge about the clinic and epidemiology (light-hard technologies). The third refers to the worker-user relationship (light technologies).

A certain arrangement of these three tools allows medical intervention to be produced with an emphasis on procedures, focusing only on technical possibilities, without observing the individual’s needs and plans, favoring, for example, the practice of dysthanasia. Other arrangements, however, can generate care-centered intervention, more attentive to the patient’s life project and more favorable to autonomous decision-making at the end of life. Based on the consumption of technology and procedures, the first approach is stimulated by the capitalist logic, which envisions in medicine a productive field of investment³².

Normalization of life

Underpinning the definitions of the individual’s life and death are concrete relations of power and knowledge. In healthcare, power is not exercised by

force, by the State apparatus, but by specific knowledge and technologies of control and organization that, under the pretext of developing well-being, subject individuals to strategic life management devices. The State is not the sole holder of power; there are several micro-powers articulated to it acting in society³³.

Disciplines act by uninterrupted coercion, scanning space, time and movement, organizing human multiplicity to facilitate the exercise of power. They perfect the body from an economic point of view, but minimize its political strength. Through them, power relations can function more discreetly, transforming confused and politically dangerous crowds into orderly and docile multiplicities^{3,33}.

Like surveillance, normalization became one of the great instruments of power at the end of the classical medicine era. It institutes parameters of normality, categorizing and distributing classes^{3,33}. The norm emerges from discipline, establishing the “common sense” as a principle of coercion already in teaching, via standardized education. And the same occurs at the hospital^{3,33}. One of the normalization strategies in medicine is the examination, which combines hierarchy and sanction. The examination gaze normalizes; it qualifies, classifies and punishes, performs the ceremony of power and establishes the truth. It is a technique of both power and knowledge – not by chance, one of the most used at hospitals^{3,33}.

From the 18th century, with the emergence of biology as a science of life, the power mechanisms turn to the body, acting on individuals via norms, knowledge, discipline and regulations³. With the changes in political law, power, previously exercised by the prerogative to let live or take life, assumes the purpose of guaranteeing, sustaining, reinforcing, multiplying and organizing life. Political technologies proliferate, investing in the body, health, food, habits and all aspects of existence^{3,33}.

In the 19th century, from control, surveillance and examination, knowledge about the human being, defining the normal and the abnormal, is conformed. Knowledge and practices begin to organize human multiplicities, homogenizing differences via discipline and normalization. Processes of social inclusion and exclusion are fueled according to the normal-abnormal binomial³³.

“Normal” now designates, besides the school prototype, the organic health status. The notion is established in several fields as a principle of coercion. In the hospital, this happens through a

medical staff capable of enforcing general norms, including life. “Normal” is to live, to have health; anything different from that is considered abnormal and unacceptable³³. Medicine regards disease and death as deviations. Its goal is to bring the body back to a healthy state, and everything is done for the individual to live and regain health. The patient who no longer wants to live evades the scientifically established norm³³.

Ways of resisting normalization are the techniques of government and care of the self, the art of not being governed³³. From the end of the 20th century, emerges a greater awareness and consequent appreciation of the fight against the subjection of individuals. Foucault³⁴ proposes alternative forms of power to modern knowledge and powers, such as biomedical sciences, focusing on the individual’s relationship with oneself.

Derived from economic and social processes, subjection is based on knowledge and powers exercised by the State, which determine forms of subjectivity. Foucault’s analyses seek forms of resistance by creating one’s own subjectivity, away from the normalizing power of laws and sciences. For Foucault, there is no other way to resist political power than starting from the relationship with oneself, centered on constituting oneself as an active moral subject³³. The concern with the care of the self has grown, changing concepts, building critical strategies and problematizing the subjects’ relationship with the “truth”³³.

Medicalization of life and death

The medicalization of life and death has been growing in the last fifty years. The scope of this process and its effects concerns health and human sciences researchers³⁵. Foucault³⁴ contributes to the debate, but his medicalization corresponds to a historical process that goes from the end of the 17th century to the beginning of the 19th century, with the emergence of biopolitics and the control of the body via sex education, psychiatric classification of perversions and construction of female hysteria.

For Foucault³, all these experiences with the human body are linked, in some way, to medicine, built as an institution of social control³⁶. This would happen by the imposition, regardless of the subject’s state of health, of systematic policies for screening the population in search of diseases, by the compulsory

psychiatric examination of defendants and the absence of non-medical bodily experiences^{3,36}.

Since the 20th century, non-medical sciences have increasingly lost ground to the medical sciences, and medicalization no longer finds limits to define what is normal and abnormal. Mental illness, socially produced, is then considered deviant. All types of problem are defined as medical disorder^{3,36}. Medicalization consists, therefore, in expanding medicine beyond its traditional field, creating new diseases when considering any previously untreatable disorder as amenable to treatment. As a result, the consumption of medicines and diagnostic methods increases, fueling the pharmaceutical and biotechnology industry^{35,37}.

Corrêa³⁸ speaks of “social medicalization,” defining it as a re-description of physiological events and social behaviors that affect medical consumption and knowledge production. The author understands medicalization as the way in which technological advances influence medicine, creating procedures and products and establishing standards of conduct. The process has unlimited expansion since any condition can be rewritten in medical terms.

Medicalization labels, describes diseases and authorizes experiences with the body in the name of “advancement” and the search for “cure,” culminating in the deprivation of the individual’s autonomy, who become passive targets of medical control devices. Medicine begins regulating people’s social behavior, hindering decision-making related to one’s own body and destiny. Members of an authoritarian group dictate norms of how other groups should behave, and patients are left with no opportunity to question expert decisions. Thus, medicalization acts as medical imperialism^{36,38}.

This process was only possible due to technological development, which, despite the many benefits, brought undesirable effects, such as the commodification of healthcare. The medicalization of life and death is a practice that evades medicine’s moral and ethical principles³⁵. However, this is not due to the technology itself, but to its misuse. The notion that technique can provide an increasingly better life gives the idea that progress would be limitless. The body, however, has limits³⁵.

With medicalization, medicine increasingly participates in the dying process. Death stops occurring at home, with family members, and becomes institutionalized. Medicine is seen as miraculous, as a knowledge that heals all; but death is inevitable, and more than just a medical issue^{35,36}.

Patient protagonism

The term “patient” reinforces the asymmetric relationship and, despite being routinely used, should be discussed, since individuals, even if they have an incurable disease, are active. Every human being has a history and the right to be informed about their illness and available therapy options. One must respect their autonomy in choosing their treatment²³. Starting from the idea of power², patients should have protagonism in decision-making.

According to Spinoza², every body has power and to be free is to exercise that power to the fullest. Consequently, individuals who have their affects regulated and restrained by impotence would be subject to servitude. The philosopher defines affects as confusing ideas, primary passions of the soul, such as joy and sadness. These sensations can increase or reduce the power of acting, which is affected by relationships, and the individuals themselves are the ones who determine remedies against these affects².

Established powers need our sadness, our negative power, to reduce the power of acting and enslave us. Thus, controlling affects would be a strategy to free oneself from these powers. To have a clear and distinct idea of these passions is to distinguish them by reason. The more an affect is under the individual's power, the more it is known, the less the mind will suffer because of it².

Franco and Galavote³⁹ analyze a case that highlights the insufficiency of the biological clinic as conceived by the hegemonic power based on the Flexner's model⁴⁰. The example perfectly illustrates the assumption that affects operate the production of self and the other, shaping ways of life by which a body asks for recognition.

The case concerns an individual who suffered an accident and was informed that his prognosis was reserved, and he had only a few months left to live. After discharge, in addition to the state of health not evolving, despite home care, the patient began to languish. However, after changing the physician responsible for the case, the recovery was remarkable.

The hypothesis for such an improvement concerns subjective aspects. With the exchange of the health professional, the individual's power of acting, hitherto inert, may have been activated³⁹. From the prognosis, the doctors made the decision to give up for the patient. When taking charge over

his life, which regains sense, the individual becomes highly desirous, powerful. In this process, the doctor-patient relationship proved to be fundamental.

The purely biological understanding of the body, as a functioning structure or system, is insufficient for effective intervention, preventing the fulfillment of the individual's needs. As a counterpoint, the concept of body without organs emerges, making other care practices possible when operating by affects³⁹.

With the knowledge of the anatomoclinic body the criterion of truth of the clinical gaze emerges, characterized by the “eye-retina,” which sees the visible plane, but not subjectivity, reducing the body to its structure³⁹. Such a clinic disregards the body without organs, centered on the relational dimension, capable of recovering its power of acting in the world – the sensitive body, incomprehensible to the “eye-retina”³⁹.

When the patient's life force is not stimulated, it is difficult to activate his desiring energy, his power for the care of the self. The individual then becomes more prone to leave the power of decision in the hands of others, those gifted with knowledge. In the case mentioned³⁹, at first the patient was seen through the lens of hegemonic thinking, as an anatomo-physiological body considered dead in the relational dimension. The individual had a bad encounter, which produced “sad passions” that reduced his desiring strength and ability to act in the world.

In the second moment, as the study reports, the affect is mutual. Caregiver and patient have their power of acting increased by “joyful passions,” and care takes a different direction. Thus, Franco and Galavote³⁹ suggest that the eye-retina is insufficient to care for those who suffer and, alternatively, propose pairing the body without organs with the anatomoclinical body. For the authors, the clinic of affects, together with the clinic of the gaze, is a necessary tool for comprehensive healthcare.

Final considerations

Issues related to end-of-life have been in evidence in recent decades, especially due to the possibilities created by biotechnoscientific development. However, although new technologies allow for several ways of dying, the central issue in this stage of life is decision-making, which must involve patients and family members duly informed about treatment options, consequences and perspectives.

Individuals who have lived their whole life based on their choices must also be allowed to choose their end. Despite the many factors that hinder decision-making, the patient's protagonism prevails. The professional must be sensitive to small gestures that may indicate decisions, such as adherence or not to treatment. These signs are the patient's own therapeutic option, who is trying to take control of their body.

In the micropolitics of care, the patient often makes decisions invisible to the eyes of health professionals, fixed by biomedicine. The individual's decision is present, it just needs to be recognized. Thus, even without cure, there are therapeutic possibilities that arise from the patients themselves. Whether it is the decision to say "enough" or go "all the way," what one decides to do at the end of one's life is part of "caring for the self".

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