The Exercise of Autonomy by Older Cancer Patients in Palliative Care: The Biotechnoscientific and Biopolitical Paradigms and the Bioethics of Protection

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ABSTRACT: Toward the end of life, older cancer patients with terminal illness often prefer palliative over life-extending care and also prefer to die at home. However, care planning is not always consistent with patients' preferences. In this article, discussions will be centered on patients' autonomy of exercising control over their bodies within the current biotechnoscientific paradigm and in the context of population aging. More specifically, the biopolitical strategy of medicine in the context of hospital-centered health care control and of the frail condition of cancer patients in the intensive care unit will be considered in terms of the bioethics of protection. This ethical principle may provide support to these patients by ensuring that they receive appropriate treatment of pain and other physical, psychosocial, and spiritual problems in an attempt to focus attention on the values of the ill person rather than limiting it to the illness.

KEYWORDS: aged, terminally ill, palliative care, personal autonomy, biotechnoscience, bioethics of protection

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Introduction

Population aging is progressing rapidly and poses a serious challenge to health policy-makers, as increased life expectancy has led to an increased incidence of chronic noncommunicable diseases. In the case of cancer, the number of new cases is expected to rise by approximately 70% over the next 2 decades. However, significant biotechnological advances have opened new avenues for an early detection and treatment intervention, allowing better disease control and a higher chance of cure.[1]

This epidemiologic transition has also resulted in a change in patient flow in the health system. More patients can be admitted to hospitals that provide complex care, and particularly to the intensive care unit (ICU).[2] Therefore, a critical reappraisal of the criteria for ICU admission of critically ill cancer patients is in order. Ill and frail older cancer patients require a careful evaluation of the potentially complex interactions of their condition with acute complications, tumor stage, and likely prognosis, and particularly with their personal values and preferences. Thus, palliative care should be considered and discussed with patients and families aiming to improve patients' quality of life, especially when such care is likely to be provided in an intensive care setting.

The biotechnoscientific paradigm has certainly entailed a change in the epidemiologic profile for chronic noncommunicable diseases and prompted discussions about the patient's personal autonomy and bodily self-determination. However, modern health services are generally oriented toward curative care, thereby failing to address concerns about the circumstances under which intensive care is applicable or whether there is room for palliative care, in an attempt to focus attention on the values of the ill person rather than limiting it to the illness.[3]

The interaction between biopower/biopolitics and end-of-life care brings about bioethical issues. There remain open questions as to what extent patients' autonomy of exercising control of their own bodies, their wishes, or what is regarded as "reasonable" in terminal care can be used for real-world decision making. This reopens the discussion of the need to change the traditional Hippocratic ethical paradigm, which is considered insufficient to deal with the extreme situations of current medical practice and confrontation with death and finitude. In particular, this raises the question of whether bioethics would be able to analyze the morality of practices in the context of biotechnoscience.[4]

Issues related to the end of life and the limitations of supportive care for terminally ill cancer patients are still neglected due to the strong influence of medical education based on the principles of the traditional Hippocratic ethics and on the extensive training for a technicist approach to illness and the body. This can be understood as an exercise of biopower (the subjugation of bodies) whereby biopolitics is put into effect in a context of health care control and excessive medicalization in a hospital-centered system whose focus remains on disease control and cure.[5]

It is therefore of utmost importance that patients' autonomy over their bodies be discussed within the current biotechnoscientific paradigm because a significant number of in-hospital deaths occur in the ICU.[6–8] Recognizing that ill and frail older cancer patients are vulnerable, discussing protective measures and minimizing the risk of harm to patients with limited autonomy are important topics that constitute the kernel of contemporary moral debate, and hence the priority given to the exercise of personal autonomy in difficult situations involving decisions that might irreversibly and substantially affect the quality of living and dying of morally competent individuals.[9]

In this article, discussions will be centered on patients' autonomy of exercising control over their bodies in the field of biomedical practices. More specifically, the biopolitical strategy of medicine in the context of hospital-centered health care control and of the frail condition of cancer patients in the ICU, which makes it imperative to address the issue of palliative care in an era of care based on patient's values and preferences, will be considered in terms of the bioethics of protection.

Discussion

The morality of biotechnoscience

Biotechnoscience aims to transform living beings and life processes based on their health needs and desires, promoting quality of life by enhancing the well-being of an individual or a population.[10] Technical and scientific developments have allowed disease control, cure, and/or cessation of suffering. However, the controversy over "interventions in the body" has also triggered a discussion on the morality of human actions in the field of biotechnoscience.

Technological advances in biomedicine and the development of invasive and noninvasive devices for life-sustaining care have undoubtedly provided benefits by optimizing disease control. However, they must add some value, be properly indicated, and/or be applied according to the disease stage. That is, the proposed benefits must outweigh the losses in terms of promoting a person's quality of life. Once the potential benefits have been checked, ethics should permeate the use of knowledge and the path to be followed in the search for well-being, whereas moral shortcomings should not prevent institutions from acting effectively and coherently.[11]

In the light of bioethics, the scientific ideal of episteme (the conscious use of scientific knowledge and methods to promote physical, mental, and social well-being) should meet the desired ethical principles of beneficence, nonmaleficence, equity, precaution, responsibility, justice, and protection—ie, to identify biotechnoscience as a source with the potential to positively affect health and, consequently, quality of life. In short, scientific progress should not be curtailed—but it is imperative to take into account the best interests of the person, with particular emphasis on human dignity.[12]

On the context of biopolitics

Biopolitics is a form of intervention or exercise of power over people's lives with the purpose of controlling the health of bodies. Biopolitics is linked to biopower, ie, power exercised at the level of subjects and also of populations.[13] In particular, the biopolitics of the human species is concerned with the populations and their demographic and endemic problems, including the form, nature, extent, and intensity of diseases (incidence and prevalence), where medicine plays a role by coordinating medical care, centralizing information, and standardizing knowledge.[14]

Foucault described the "statization of the biological" (classical theory of sovereignty), in which the right to "foster life" or "let die" belongs to the State; it is the power to take life or allow to live in a care perspective.[14,15] It is in such philosophical and political debate that we can perceive the exercise of (bio)power over the lives of citizens through the development of technologies and the control that is exercised over them.[16–18]

In this context, the philosopher Giorgio Agamben[19] suggests the resemantization of the Greek word *zoè* from "life" into "bare life," characterizing the existential condition, ie, life that is abandoned and threatened by biopolitics. By addressing these concepts of life, 2 ethical principles may be confronted in a moral paradigm: the sanctity of life and the quality of life. They delineate the field of moral conflicts faced by bioethics: The first is based on the intrinsic finitude of human existence or divine plan, with no attempted opposition, and the second is based on the legitimacy of interventions to reduce avoidable suffering and promote well-being.[20]

The issue of autonomy

Autonomy implies that individuals are capable of self-government; they are able to review their possibilities and understand their rights and duties without internal or external constraints.[21] With the advent of medical technology in the 20th century, medical practice has gradually changed to meet patients' needs. However, ill and frail older cancer patients continue to receive aggressive end-of-life curative treatment despite evidence that such high-intensity treatments do not improve their quality of life or outcome.[22] Actually, an increasing number of in-hospital deaths have occurred in the ICU, even though most patients have expressed that they would prefer to die at home.[23]

Factors prompting attention to the debate involving end-of-life decisions and how to die (well) include the recognition that "doing everything possible to prolong life"—such as ICU admission, invasive procedures, radiation therapy, and chemotherapy for terminally ill cancer patients—is not always appropriate or desirable.[24] Because attention is focused on the disease, a relationship is established with the illness rather than with the ill person. In this relationship, the patient is a passive, uninformed recipient rather than an active, informed individual, and the right to self-determination becomes a "right to be represented" in end-of-life decisions.

Physicians often assume a position of power and control whereby they hold themselves responsible for the patient's illness, acting with authority to determine the best interests of the patient. This temporary abdication or denudation of power until "everything is resolved," ie, for the period during which one is a patient,[25] may be interpreted as an act of deliberately "*vulnerabilizing*" the patient. This gives patients little or no choice over the matter, rendering them vulnerable to real pain and/or suffering. This is to violate a person's autonomy—treating that person merely as a means, in accordance with others' goals without regard to that person's own goals.[26]

The palliative care perspective

Palliative care is an approach that helps terminally ill patients and their families deal with the uncertainties that are part of progressive disease. Although palliative care is recognized as a distinct medical specialty in many countries,[27] varying slightly in the structure of programs according to local health policies, it remains underdeveloped in most of the world, especially in low-to-middle income countries.[28]

Palliative care aims to improve the quality of life of patients and their families by relieving patient suffering and managing pain and other physical, psychosocial, and spiritual problems.[29] Although patients are more likely to receive palliative care as they get closer to death, it is not intended to either anticipate or postpone death. The World Health Organization recommends the provision of palliative care as a support system that helps patients live as actively as possible until death and families feel assisted throughout the process of illness and grieving.[30] Therefore, it should be initiated as early as possible to positively influence the disease course.

There may be some variation in end-of-life-practices between and within countries based on their different cultural backgrounds and how traditional religious or atheistic views deal with the end of life. Although death-avoiding cultures persist in many countries, particularly in some low-to-middle income countries, evidence supports benefits from standardized, goal-related communication and ICU-based palliative care practices. Therefore, ICU providers should embrace proactive goal-related communication with patients and peers,[31] as our duty in palliative care is not to find new ethics but to act simply ethically.

Predictions of a considerable increase in the world population aged 60 years or older may similarly lead to an increased number of elderly people with conditions that will need specialized care, which may have a more dramatic impact on countries whose economy is characterized by low to medium income.[28] In the palliative care model, studies have shown a reduction of 30% in emergency department visits and 28% in hospital admissions, with spending per patient/per month being reduced by $18 000 compared with a curative care model.[32] In another study, patients receiving palliative care vs standard oncologic care were less depressed (58%) and received less aggressive end-of-life care (39%), and median survival was longer by several months.[33] In the United States, 80% of the citizens would prefer less aggressive end-of-life care, avoiding hospitalization particularly during the terminal phase of illness, and would also prefer to die at home, avoiding ICU admission.[34] However, despite expressing their willingness to die at home, approximately 55% of patients are deprived of their autonomy and actually die in the hospital.[32]

Despite conventional complex treatments and biotechnological resources available in ICUs, the establishment of appropriate palliative care is still required in low-to-middle income countries. It should be delivered by health care providers who are trained in medical ethics to respect the patient's will and made available to everyone who faces a life-threatening illness, regardless of income.[28] However, in almost all cases of older cancer patients admitted to the ICU in middle-income countries, such as Brazil, a more comprehensive health promotion approach within palliative care is not usually offered to patients. In fact, little is known about end-of-life care decisions made from ICU admission to death. A study of adult cancer patients conducted in Brazil reported that such decisions are made on average within 4 days (interquartile range, 2-10 days) of ICU admission.[35,36] In this setting, once end-of-life care decisions are made, patients are rarely discharged from the ICU. Do-not-resuscitate (DNR) orders and orders to withhold life-sustaining and life-prolonging treatments are more common than orders to withdraw treatment. Therapeutic measures, such as cardiopulmonary resuscitation, renal replacement therapy, use of vasoactive amines, and blood transfusions, are more often withheld in the ICU setting, whereas artificial ventilation, fluid replacement, and artificial nutrition are less frequently withdrawn or discontinued.[37]

Because some patients are too ill to make decisions for themselves, the burden of decision making falls on family members, which may cause hesitation and limit the indication of treatment. In this decision-making context, the possibility of a time-limited trial (TLT) may provide a treatment alternative to more invasive interventions across previously identified outcomes, as it can facilitate decision making over time. Time-limited trial is an agreement between physicians and patients/family to use certain medical therapies over a defined period to observe whether the patient improves or deteriorates according to agreed-on clinical outcomes. In fact, physicians should always question whether an intervention is to be continued (balance between clinical response and toxicity) and whether iatrogenic harm is to be minimized, patient burden reduced, and health care costs contained. When deterioration occurs, TLT treatment is withdrawn and palliative care becomes the main goal of care.[38–40]

For intensivists, geriatricians, and palliative care specialists, TLT is an appropriate and powerful tool that facilitates value-based, goal-oriented decision making. It is suitable for a broad spectrum of prognosis and care priorities, allowing to recognize that a patient's prognosis and goals of care can change over time. Time-limited trial has been used across a range of clinical contexts as an approach to the management of the critically ill in poststroke care, end-stage renal disease, and obstructive pulmonary disease, as well as in the surgical care of the frail elderly to tailor difficult care decisions to individual patients' priorities and highlight important considerations that might otherwise be overlooked.[38]

Caring for ill and frail older cancer patients is dependent on complex efforts involving medical, social, and psychological aspects, which may be addressed more efficiently by an interdisciplinary and patient-centered approach focusing on the patient's values and interests. Thus, geriatric palliative care should support the exercise of personal autonomy by preserving patients' desires and values while expanding their access to information and choices. A multidimensional evaluation with early identification of physical, cognitive, or psychosocial problems is needed to plan timely and effective interventions to relieve symptoms, prevent complications, and reduce associated risks such as functional dependence and unnecessary hospitalization.[41]

It is generally recognized that palliative care is an important component of critical care, whatever the stage of illness, and an indispensable tool for patients with advanced-stage chronic conditions who are heading toward the end of life. However, such care remains unavailable for a large proportion of the world's population, especially in low-to-middle income countries. Therefore, for the sake of caring ethics and patients' dignity and overall well-being, palliative care must urgently be made an essential component of care for the management of these patients.[42,43]

The proposal of the bioethics of protection

Bioethics is a discipline that examines the morality of human acts that can irreversibly change the processes of living systems. It offers tools to analyze, describe, understand, and solve potential conflicts of interests resulting from the relationship between health care providers and vulnerable patients, which includes palliative care.[9,44,45] In this scenario, the bioethics of protection arises to provide support for patients' essential needs and has been used to assist in the resolution of moral conflicts that involve the provision of dignified care to older cancer patients, particularly in the intensive care setting.[46] The challenge of physicians is to provide medical interventions that are humane and helpful to patients in the individual case. The basis of medical ethics is largely independent of the available technical possibilities, as the focus should be on the ill person rather than on the illness or the medical techniques specific to his or her treatment. However, the question lies in whether the means used by health care providers to "foster life" can actually meet the expectations of care of older patients with chronic critical illness, as in the case of cancer patients admitted to the ICU.

Acutely ill patients and ill and frail older cancer patients often receive the same life-sustaining treatment when admitted to the ICU. However, the key point is that their outcomes are different because older cancer patients are often maintained in these units in a state of prolonged organ failure and not rarely in (persistent or permanent) vegetative condition, causing unnecessary suffering to both patient and family by prolonging the dying process.[47] The wide range of options available in contemporary medical science and the biotechnological apparatus available in ICUs may also lead to a distressing form of suffering: dysthanasia—hardly contemplated by health care providers.[48] Therefore, according to the concept of respect for patients' vulnerability, the term "protection" becomes the moral principle of greatest importance in guiding actions in the field of biotechnoscience, which should include an attitude of consideration, appreciation, and compassion.[48]

Regarding patients' autonomy in the doctor-patient relationship, issues such as the DNR decision or the decision not to initiate a replacement therapy, such as dialysis or mechanical ventilation, should be discussed during advance care planning and clearly described in the patient's records. Thus, older patients' autonomy can be enforced by means of documentation in the form an advance care directive (ACD) aiming to ensure the provision of care aligned with the patient's expressed wishes, even in the event of subsequent partial or complete cognitive impairment. Advance care directive represents a significant advance in health care and derives from the ethical freedom of the individual, in agreement with major social transformations that have enabled its wide acceptance.[43] Advance care directive should also address situations in which consideration might be given to limitation of what is technically possible.

It is in such environment that we should clearly consider the 2 terms to which protection applies: the vulnerability of the human existential condition, inherent in all living beings, and the act of deliberately "*vulnerabilizing*" the ill person, interpreted as a specific existential condition in which patients, regardless of their will, values, and preferences, are given little or no choice over what happens to them, having no means to resist or face adversity.[49] The purpose of protection is to provide a "minimum" essential moral value to guide conflicts of interests while taking into consideration the act of "*vulnerabilizing*" the patient—the actual situation in which older cancer patients, admitted to the ICU, are subjected to highly complex therapeutic invasive procedures despite their frail condition. Therefore, the bioethics of protection is presented as a suitable reference for resolving conflicts in the care of ill and frail older cancer patients, with special attention to situations involving loss of functionality, in an attempt to stop treating these patients as merely vulnerable, but rather viewing them as patients who are "*vulnerabilized*" and, therefore, in need of protective actions.[10,49]

Conclusions

The moral conflicts that emerge from the application of biotechnoscience and biopolitics to older cancer patients in the ICU may be legitimate objects of the bioethics of protection.

This ethical principle can provide support to patients in situations of imposed threat due to their vulnerable, or "*vulnerabilized*," condition. Studies on palliative care may solve the clash of the technical expertise of medicine and its curative treatments, which are still limited despite the advances in biotechnoscience. Moreover, these studies may shed some light on the culture of respect for the patient's personal autonomy, especially regarding extreme decisions, such as allowing patients to decide whether they want to continue living in suffering or not.

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Author Contributions

MNG developed the structure and arguments for the manuscript. MNG wrote the first draft of the manuscript. MNG and FRS contributed to the writing of the manuscript. MNG and FRS made critical revisions and approved final version. All authors reviewed and approved of the final manuscript.

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