

# Cancer: a perspective of human dignity and informed consent from ethics and justice

## Cáncer: Una perspectiva de la dignidad humana y el consentimiento informado desde la ética y la justicia

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### ABSTRACT

This article attempts to reflect on the importance of thinking in general about illness and about cancer, from an ethical perspective. This approach reveals the central role of personal dignity and the moral relevance that supports the reasons for respecting people. The ethical values that sustain the practice of medicine must aim at uplifting this dignity and seeking situations of justice, since living in a community expresses intersubjectivity that cannot be truncated by illnesses like cancer. Therefore, situations involving poverty cannot justify the lack of health care, and if such lacks occur, they run counter to ethical awareness in the deepest sense and destroy intersubjectivity. As a result, cancer is suffered as a vital experience, in a framework of lives that are lived and are not simply objects of study; those stricken with cancer are individuals who are denied the human right to health, and undergo the elimination of their dignity, the cancelation of justice, and a death sentence. Society is part of these actions and at the same time, suffers from the disappearance of hope.

In this sense, the process of informed consent is used as a tool that encourages dialog and understanding between doctors and patients during proper treatment, on a shared path.

**Key Words:** Cancer; ethics; human dignity; social justice; poverty; informed consent (*source: MeSH, NLM*).

### RESUMEN

El artículo pretende hacer una reflexión sobre la importancia de pensar, en general, la enfermedad y, en particular, el cáncer, desde una perspectiva ética. Este acercamiento permite vislumbrar el papel central que tiene la dignidad de las personas y la relevancia moral que apuntalan las razones por las cuales ellas han de ser respetadas. Los valores éticos que sustentan la práctica médica han de apelar a enaltecer dicha dignidad y buscar situaciones de justicia, dado que vivir en comunidad da cuenta de una intersubjetividad que no puede ser truncada por enfermedades como el cáncer. Esto evidencia que las situaciones de pobreza no pueden justificar la carencia de cuidados de salud y que, cuando esto sucede, se contraviene, desde lo más hondo, una conciencia de carácter ético y se rompe la intersubjetividad. El cáncer se sufre en tanto experiencia vital, en un marco de vidas vividas y no simplemente de objetos de estudio; los enfermos son personas a quienes se les niega el derecho humano de la salud, se les borra su dignidad, se cancela la justicia y se les condena a la muerte. La sociedad es parte de estas acciones y a la vez sufre la cancelación de esperanzas.

En este sentido, se retoma el proceso del consentimiento informado (CI) como una herramienta que permite el diálogo y la comprensión entre médicos y pacientes en la atención digna, en un camino compartido.

**Palabras Clave:** Cáncer; ética; dignidad humana; justicia social; pobreza; consentimiento informado (*fuentes: DeCS, BIREME*).

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Cancer is a disease with one of the highest frequencies and mortality rates at the international level. It is the second most common cause of death, causing 8.8 million deaths in 2015; this figure increased to an estimated 18 million new cases and 9.6 million deaths in 2018 (1). The WHO predicts that due to changes in the birth rate and aging, by 2030, new cases will exceed 20 million per year (2).

In such a scenario, it is worthwhile to point out that approximately 70% of deaths from cancer occur in middle- and low-income countries, and that only one in five middle- or low-income countries have the necessary data for promoting policies to fight against cancer (3). The detection of cancer in advanced phases and the absence of timely diagnosis and treatment are frequent problems. In 2017, only 26% of low-income countries reported that their public health sector had pathology facilities to serve the general population, while more than 90% of high-income countries offer treatment to cancer patients (2).

As a consequence, this study will analyze from impoverished contexts, such as those of Latin America, some of the basic needs that must be met to attain a minimum of humanizing life. This is a required topic for ethics as well as for individuals seeking medical attention. The topic of health and universal, high-quality access to health care cannot be ignored, since it is a central question that invokes and defends personal dignity. We propose informed consent as a dialogical tool for expanding ethical frameworks and horizons between the doctor and patient. Such consent extends beyond a simple authorization form; it is a process “that consists of a person's express manifestation to participate in research, in conditions that permit knowing the risks, consequences, or problems that may occur during the research in which the person will participate” (4).

### Cancer from an ethical/philosophical discussion

In recent years, much has been said about the complexity and the complex systems in philosophy that have revolved around cancer. We do not intend to review all of those positions here, but instead shall center on discussing ethical recognition and the human dignity involved in cancer (5).

In medicine, and specifically in cancer treatment, ethical decisions have a fundamental social function. Deciding among a variety of options for novel treatments versus conventional possibilities can be a difficult task to accept. Selecting treatment, without neglecting the patient's dignity and autonomy, or abandoning scientific and medical integrity, can be an ethical dilemma. Ethics habitually arises when a choice must be made between two equally risky or difficult medical situations. Using and maintaining

all the therapeutic possibilities that scientific/technical development offers in the attempt to save a life can be an obstacle or represent continual, stubborn aggression (6).

Accompanying a person who has cancer in any stage--whether during diagnosis, treatment with its respective repercussions, and other possible stages such as participation in experimental treatment, or palliative care and the control of symptoms--is a challenge for the professionals of oncology (6).

We must not neglect, however, to recognize the dignity that requires establishing health care as obligatory for all individuals: duly available for all, and because of its ethical nature, a right. This ethical nature is configured with the defense of dignity that is expressed in providing health care for illness in general and specifically, for cancer: an illness for which treatment is very costly and unaffordable for most of the population.

Confronting cancer positions us before the moral condition that is paired with individual humanity, because individuals and their community are without exception *homo moralis*. This means that “moral reality is constitutively human [...], a need required by psychobiological structures themselves” (7). The human organism is suspended among outside stimuli due to the absence of an organic predetermination to that environment; therefore, “somatic structures require intelligence along with morality” (8). In this sense, even to subsist biologically we need to take charge of the situation we are facing--such as cancer--to determine how it challenges us as well as others, including doctors. In these actions, we have limited freedom for responding in diverse ways, because of shortages and generalized economic constraints with regard to treatment costs. Such negative freedom is insufficient to ensure a wide variety of moral actions, since possible choices are quite reduced. Humanization depends precisely on managing events that must be handled in joint form and thus unfailingly imply paradoxical hope.

The process of humanization depends on the moral commitment to self and others: an “obligation that is not imposed from the outside but arises from within the individual who becomes aware of his moral condition while his interest in living and growing is activated” (8). Dehumanization betrays such morality, perverts and damages what is human, and points to the importance of thinking about health, which in our precarious contexts can be offered or denied. Health necessarily involves living a fruitful life because health is good for people; any pathological development truncates an individual's existential possibilities by defying life itself, curtailing the “not yet” that is implied by hope.

In this manner, the actions performed with respect to cancer include alternatives that are susceptible to evalua-

tion, which implies freedom and rationality: two elements of the moral condition of humanity that is grounded in dignity. Freedom as a presupposition of the moral condition can be (as we suggested above) negative--freedom "from"--or positive-- freedom "to". The first refers to the determinations that subject us and prevent our making decisions, such as poverty; however, when such determinations are resolved or at least muffled, they permit the freedom "to" be able to humanize fully. For this reason, freedom "from" isolates dignity by blocking its action. It is important to state that the presence of pathology and the possibility of cure reveal the moral foundation that is inevitably associated with a social and cultural context. If actions aimed at curing cancer are possible, freedom "from" moves to freedom "to"; in other words, individuals may, although still under treatment, carry out their projects. Such are the possibilities of a moral nature that medicine can encourage or limit. And they are the source of the relevance of medicine in the humanization of life for members of society.

We well know that social and institutional contexts can help or fail to help face the pathologies of health; they can humanize but can also dehumanize by sacrificing individual needs, in the interest of the system's needs. Such situations have ethically negative consequences because the values health promoters and health providers sustain do not promote a *good life*. The system thus dehumanizes individuals. As a result, reigning values must imply the defense of dignity that serves as a fundamental value, as well as other values like justice, which accompanies the central value of dignity.

This task is performed by the values stated in the Hippocratic Oath; the document dates from a time of major advances in ancient culture, the Golden Age of Greece when the arts and letters flourished. As the era was marked by interest in finding solutions for illness, the Hippocratic Oath certifies and reiterates medical actions that offer and support a logic of co-participation and the sharing of acquired knowledge, in an attempt to meet the needs of others, to the benefit of the sick, in order to "abstain from all intentional wrongdoing and harm" (9).

It is important to emphasize that the Hippocratic Oath has been updated as a physicians' oath of professional loyalty, and it assumes with full force that physicians promise to consecrate their life to the service of humanity. At the same time, physicians taking the oath promise to exercise their profession with care and not allow considerations of various types--such as social standing--"to intervene between my duty and my care" as they "maintain the utmost respect for human life" (9): in short, the respect for dignity.

As a consequence, rethinking human dignity from the parameters of ethics and justice with respect to cancer is a commitment to our reality and a recognition of the humanizing values that must be reviewed when dealing with illness among the people around us.

If we do not want our actions to be mere gestures in empty space, they must be based on reasons involving justified, supported values (10). The reasons for defending health are grounded in values that understand the worth of health, and such comprehension prevents the trivialization or superficiality that would imply the destruction of reason. Actions based on the foundations of value lead to social and political proposals that address the core of the difficulties in giving and returning health to those threatened by the loss of health. This is the challenge and the way that such actions acquire meaning.

Moving toward a real, non-illusory value like the scope of health enables remedies for shortage; attempts to do so mean that the intentional action can have an effect on the world (10), leading to a community of individuals who can have a better life in the face of illness. This is why a moral conscience--the capacity for the moral judgement that allows us to evaluate human behaviors--is so relevant for orienting individual actions as a function of the value of dignity and justice. Such a conscience is backed by reason that implies feelings as affective qualities, in addition to the intellectual knowledge of good and bad. That moral conscience is necessary to orient us in our existence; it is a humanistic conscience that describes human potential as a moral being and therefore is a condition of a humanizing moral praxis.

Perceiving dignity as valuable is due to a designation of the degree or quality of dignity, and reveals that dignity is the ability to affirm ourselves as valuable beings. That value must be protected plainly and simply because it is attached to individuals (11). It is care and protection in the presence of pain, fear, slavery, ignorance, discrimination, and exclusion, among other ills. Seneca referred to this concept when he sustained that *Homo res sacra homini* ["Man is a sacred thing for man"], a consideration that involves the issue of human relations and is committed to mutual care and safeguarding. Respecting an individual for possessing human dignity is considered to be characteristic of a moral agent who carries out actions and claims (12).

The search for justice is also an observance that means not subjecting individuals in any way to exclusion or harm, which annihilate personal dignity and destroy autonomy and agency. Preventing people from leading a life that meets their fundamental needs for food, housing, health, education, freedom, and the construction of identity (13) is equivalent to crushing dignity. Violating limits

and causing harm threatens dignity. The role medicine plays--in this respect--is fundamental for enabling dignifying plans for living.

Thinking about the situation of a sick person in a community obligates us to consider dignity from an ethical/virtuous sense (14) because it calculates dignification based on completed actions, with proof of purpose shared with others. Such intentions reveal virtuous excellence with others, always and inevitably. In this case, dignity is framed by the recognition of rights and an approximation to justice. The “right to have rights” (15) is fundamental upon recognizing the substrate to which that right is attached: most precisely, dignity. Attached to dignity are the moral values related to the behavior that dignifies the person who performs the action as well as the person who receives the action. The reasons for treating a person with dignity and respect is that such treatment dignifies others as well as ourselves, in a community sense of recognition and compassion.

Practical rationality--which seeks action--concretely determines moral behavior on considering the unique circumstances and lessons of moral experience. It is practical knowledge relative to actions, to the behavior that takes circumstances into consideration. Such practical rationality or phronesis is also willingness accompanied by reason that is directed to action (16). It is a virtue put into practice by a deliberative subject, and it is through such action toward health that we make ourselves dignified with others, as we make them dignified. These actions are fundamental for confronting illness and echo the proposals of the Hippocratic Oath.

In this setting it is convenient to enquire about the mechanisms and instruments that must permeate the doctor/patient relationship, the agreements and criteria that must determine the relationship of a professional who aspires to cure a patient who is suffering from illness. In this sense, dialog, reasons, and agreements between the two actors are fundamental for achieving concerted action having the unarguable value of dignity and the best reasons for dealing with cancer. We therefore consider it pertinent to rely on informed consent as a basis of dialog.

### **Informed consent as a dialogical process between patients and physicians**

Medical knowledge compiled as evidence does not justify abandoning the procedure of informed decision making. The patient must continue deciding between uncertain benefits and unknown risks. Informed consent, more than a form or a legal requirement, is thus an “opportunity to adequately empower patients, and along with them assume in a responsible manner the risks and benefits of

the treatment or treatments to follow” (6), encouraging the freedom of having elements for making decisions. The knowledge of such reasons supports human dignity by offering possibilities for agency and making decisions with regard to illness.

Obtaining informed consent is a process that begins on initial contact with the patient, by providing information, repetition, and explanations in an understandable, unbiased manner, answering questions as they arise, and ensuring that each person adequately comprehends what will occur during treatment. This process shows respect for dignity and recognizes personal autonomy, and therefore requires sufficient time, including time to consult with those considered pertinent for making a free, uncoerced decision (17). Physicians have the duty and responsibility to ensure (17), on one hand, that they have communicated a description of the treatment in a clear and complete manner, and on the other hand, that the patient has adequately understood all the information about carrying out the project, along with the patient's own role. Evaluating individual comprehension of the information given and received is not simple. Beyond the criteria that stipulate, even legally, the identity of the competent person who is able to decide and understand the information provided, or comprehend the information provided for obtaining consent, the process depends on the communication between two moral agents (18) in a particular context while obtaining informed consent.

The formalization of obtaining informed consent can have various alternatives, whether expressed in a clear verbal manner or signed on a consent form (19). The process of informed consent ends when the responsibilities and commitments that the medical team agreed on morally with the patient have been fulfilled or covered (4).

However, at this point we must emphasize that the process of informed consent is insufficient without the willingness to participate in a dialog, and to listen and understand the other in the broadest sense. With dialog and some of its forms--such as conversation--the aspiration is comprehension, as it concerns our life experience and its characterization as praxis of the art of understanding others under the suppositions of the consideration of otherness. Since otherness necessarily involves dialog, if we are able to participate in dialog in spite of complicated situations and our own tendencies, we will be able to reach agreements and establish dignifying situations (14).

During the process of informed consent, both the doctor (medical team) and the patient are faced by conflict. The resolution and transcendence of conflict requires a position that considers otherness. An appeal is thus made to the listener as the indispensable means of opening a

fruitful dialog that assumes inclusion and understanding. With openness and imagination, “dialog is possible between individuals with diverse temperaments and diverse political opinions” (2o) or opinions of any type. We assume with Gadamer that “the capacity for dialog is a natural attribute of human beings” (2o), and that true dialog must assume an attentive listener to give credit to what the other is saying, in pursuit of mutual understanding; as a result, agreements will be reached in situations in which conflicts are settled and transcended.

Such dialog is alive: a Socratic/Platonic dialog that seeks agreement through affirmation and reply that implies the other's consideration at all times, with an appeal to that relationship and to good will. Such agreements, although difficult, are always assumed to be moral ideals (14). It is fair to believe that “in the search for understanding, there is always good will” (2o). With good will, a step is taken toward inclusive policies that address social conflicts in an attempt to implement situations of health; as a result, consideration is given to the obligatory implications of a political nature (14) that influence the forms of approaching the treatment of cancer from humanizing forms.

Human dignity and informed consent from a perspective of ethics and justice and with regard to cancer, constitute interrelated elements for attaining humanization. Yet informed consent is not sufficient for clinical research and medical practice to be ethical and human. Health as an asset to safeguard is granted to the physician, who remains in charge of defending dignity, life, and health as priority values for the sick. In the actions of treatment, the true owner of life is the patient, who trusts the expert to exercise a complete practice with respect to the illness. The doctor/patient relationship is not symmetrical since the patient lacks sufficient means to restore health; the doctor cures, but it is the patient who in every case “is cured” (6).

In this manner, the process of informed consent can be an effective tool that permits dialog and understanding between the sick patient and the physician with respect to cancer. It is without doubt a way of humanizing treatment and the decisions that must be taken--decisions that at the deepest level defend personal dignity as well as individual justice ❖

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