

# Decision-making process in end-of-life care

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## Abstract

This study discusses ethical issues related to decisions about end-of-life care. The decision making process in clinical bioethics was selected as a basis for the study. Additionally, criteria for assessing and adopting positions on end-of-life issues were analyzed, including the necessity of including (or their substitutes), family members and healthcare practitioners in the decision making-process, in an atmosphere where respect for autonomy – with all its nuances and limitations – plays a key role.

**Keywords:** Bioethics. Decision making. Ethics. Terminal care. Medical care. Palliative care.

## Resumo

### Processo de tomada de decisão nos cuidados de fim de vida

O presente trabalho discute questões éticas atinentes à tomada de decisão no contexto dos cuidados de fim de vida. Elegeu-se o processo decisório em bioética clínica para tal propósito. Analisam-se, ainda, critérios para a deliberação e o posicionamento ante os problemas relacionados ao fim da vida – os quais devem envolver enfermos (ou seus representantes legais), familiares e profissionais da saúde –, em um âmbito no qual o respeito à autonomia, com todas as suas nuances e limitações, tenha lugar de destaque.

**Palavras-chave:** Bioética. Tomada de decisões. Ética. Assistência terminal. Cuidados médicos. Cuidados paliativos.

## Resumen

### Proceso de toma de decisión en los cuidados de fin de vida

Este texto habla de cuestiones éticas relacionadas con la toma de decisiones, dentro del contexto del cuidado de final de vida. El proceso de toma de decisiones en bioética clínica fue seleccionado para este fin. Se analizan, además, criterios para tasar y adoptar posturas en cuestiones de final de vida – los cuales deben implicar a los enfermos (o sus representantes legales), familiares y profesionales de la salud –, en una atmósfera en que el respeto a la autonomía, con todos sus matices y limitaciones, desempeña un papel fundamental.

**Palabras-clave:** Bioética. Toma de decisiones. Ética. Cuidado terminal. Atención médica. Cuidados paliativos.

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Declaram não haver conflito de interesse.

(...) *un camino es sólo un camino y, si sientes que no debes seguirlo, no debes seguir en él bajo ningún concepto. Para tener esa claridad, debes llevar una vida disciplinada, sólo entonces sabrás que un camino es nada más que un camino y no hay afrenta, ni para ti ni para otros, en dejarlo, si eso es lo que tu corazón te dice.*

(...) *A path is only a path; if you feel you should not follow it, you must not stay with it under any conditions. To have such clarity you must lead a disciplined life. Only then will you know that any path is only a path and there is no affront, to oneself or to others, in dropping it if that is what your heart tells you to do.*

Carlos Castañeda <sup>1</sup>

Decision-making in issues regarding the end of life – notably euthanasia, assisted suicide, dysthanasia, orthothanasia and palliative care <sup>2</sup> – has assumed a growing contemporary prominence due to: a) the extension of biotechnoscientific paradigms and the advance of biotechnology; b) the complexity of care in health services (such as intensive care units and life support treatments that prolong life); c) an aging population; d) an increase in chronic diseases; e) the lack of palliative care services <sup>2,3</sup>. As a result the practices and circumstances that surround death have changed, so that often healthcare professionals – especially doctors – take responsibility for determining *when, where and how* a patient should die, in situations in which many such patients are hospitalized and in their final moments of life <sup>4,5</sup>.

In such situations there is justified fear caused by the genuine possibility of suffering, which may be the result of prolonging life at all costs, even when there is little or no chance of recovery or of a dignified human existence, which is always the desire of the patient. There is also a fear of the ineffective treatment of pain and of further health complaints (with biological, psychological, social and spiritual repercussions), the non-execution of comfort measures and hygiene, isolation and abandonment by health teams and/or family and friends <sup>4-7</sup>. Some definitions are therefore important for a proper understanding of the issue:

- a) *a terminal patient* is a seriously ill patient, or one with a severe, incurable disease, who does not respond to any known treatment and finds him or herself in a process the outcome of which is death and who may, in general, have up to six months left to live <sup>8</sup>;
- b) *a patient receiving end of life care* is one whose prognosis envisages 72 hours to a week of surviv-

al before death. It is a definition commonly used in oncology and other medical specialties for the correct management of the signs and symptoms presented by the patient, taking into account the natural history of the disease, the prognostic evaluation, and its impact on the functional status of the patient – *performance status* (PS) <sup>9</sup>.

A wide-ranging discussion of the bioethical process of decision-making in issues of care surrounding death and dying is urgently needed, to guarantee that the dying moments of patients are experienced with quality and dignity. This debate becomes even more necessary when the autonomy of the patient is expressed (such as by informed consent and advance directives), either by the patient himself (or herself) or by his or her legal representative, with respect to rejecting interventions that can unnecessarily prolong life, while always respecting the wishes of the patient.

Seen as a fundamental element of medical practice, decision-making requires health professionals to reflect on the choices they make so that they come to decisions which are correct and best for their patient, from the patient's point of view, which not only consider technical and scientific factors, but are also ethically pertinent <sup>10</sup>. Such a process should take into account the perspective of the care giver – the health professional – and also respect the autonomy of the patient, whilst avoiding simply transferring the decision-making responsibility to said patient <sup>11</sup>.

Therefore the aim of this article is to consider the medical and bioethical aspects of the decision-making process regarding end of life issues, using the following structure: a) concepts of bioethics; b) definition of the respect for autonomy principle; c) key end of life issues; d) burden on the decision maker; e) the decision-making process itself.

## Concepts of bioethics

The term “bioethics” covers multiple meanings, especially concepts such as “ethics of life”, “ethics of quality of life”, “biomedical ethics” or “ethics applied to the field of biomedicine and health”. In fact, delineating the semantic interpretations of the term is a significant problem. Some of the controversy surrounding the definition of bioethics can be found in the article “Bioethics and communication in oncology”, by F. R. Schramm <sup>12</sup>: (...) *a) some definitions are overly broad, such as “ethics of life”, which suggests that all ethics are necessarily*

bioethics, which, if we understand bioethics in a narrow rather than wide sense, is false; b) others are too restricted, such as “biomedical ethics”, which in practice can be confused with what is traditionally understood as medical ethics, ignoring new descriptions arising from applied ethics and bioethics, due to new questions about the process of living, falling ill and dying, as a result of advances in biomedicine and the emerging society of “consumers”<sup>13</sup>.

In this context, Schramm cites Miguel Kottow, for whom bioethics is characterized as a set of concepts, arguments and norms that value and ethically legitimate human acts [whose] effects deeply and irreversibly affect, in a real or potential sense, living systems<sup>14</sup> considering biomedical know-how, marked by the extent of the biotechnoscientific paradigm<sup>11</sup>, and the centrality of human actions and the decisions taken prior to such actions. Therefore, bioethics, like applied ethics, should suggest patterns of action that are universally suitable for a morally oriented community and have been improved in accordance with the best arguments available<sup>11</sup>. To this end, the discipline must address the description of the problems, and the prescription of the best form of conduct, taking into account<sup>11,12</sup>:

- 1) *the descriptive aspect*, which presupposes the understanding of the factors at stake in a given moral problem and the subsequent analysis – rational, impartial and reasonable – of the arguments in question according to a certain ethical theory. It is therefore concerned with scrutinizing the arguments in their specific contexts, and after ensuring clarity, allowing the choice of the most appropriate or the least controversial response to the issue under discussion;
- 2) *the prescriptive aspect*, which is the practical consequence of the previous phase, consisting of indicating and recommending the most suitable solution to the issue in question, considering assumed values, the categories of analysis and the circumstances of the case.

It should also be noted that Schramm<sup>15</sup>, in delineating the bioethics of protection, proposes a third phase – protective – as follows: *The bioethics of protection (...) is aimed at conflicts of interests and values that emerge from the practices [human], and in order to be able to resolve such conflicts, (a) is concerned with describing and understanding them in the most rational and impartial manner possible; (b) is concerned with solving them, by proposing tools that can be considered, by any rational and reasonable moral agent, appropriate for outlawing incorrect behavior and prescribing what is believed*

*to be correct; and (c) that, thanks to the correct articulation between (a) and (b), provide the means to sufficiently protect those involved in such conflicts, ensuring that each life is compatible with another*<sup>16</sup>.

The articulation of description, prescription and protection – this last, indeed, is truly a *product* of the two previous actions – may result, according to Schramm, in tools for making decisions about *what can* and *what should be done*, which obviously includes aspects related to fragility, vulnerability and finitude, intrinsic elements of the human condition<sup>15</sup>. For this, the following issues must be discussed: a) the theme of the decision to be taken – in this case, the end of life; b) who is to make the decision; c) how the decision is to be made, taking as a starting point the importance of role of respect for autonomy in contemporary bioethics. Such aspects will be considered further below.

### The respect for autonomy principle

“Autonomy” is a word derived from the Greek *auto* (self) and *nomos* (law, rule, standard), originally expressing the idea of self-government, and which, when applied to the person, refers to the self-determination of making decisions about one’s life, including in such areas as health, psycho-physical integrity and social relations<sup>17</sup>. To be autonomous is to have freedom of thought, to be free from internal or external constraints and to be able to choose between the alternatives that are presented<sup>17-20</sup>.

In the Western tradition, it was Immanuel Kant who developed, in the 18th century, a conception of ethics founded on the idea of *duty*<sup>21</sup>, but above all in the concept of autonomy of reason<sup>22-24</sup>. As a result Kantian ethics conceive a rational free will, which is fully expressed in the categorical imperative: *Act only according to that maxim whereby you can, at the same time, will that it should become a universal law*<sup>25</sup>, valid for all rational subjects. The maxim which states that the exploitation of others should be prevented – *act in such a way that you treat humanity, whether in your own person or in the person of any other, never merely as a means to an end, but always at the same time as an end* – should also be noted<sup>26</sup>.

Autonomy<sup>25</sup> – or the respecting of it, to be more accurate – is one of the pillars of principlism proposed by Beauchamp and Childress<sup>27</sup>. In fact, the authors, after repeated criticism, argue that *autonomy* should not be just another bioethical principle, but also a quality of human beings, which would allow them *self-government* to decide for themselves, according to their choices. This quality, historically

delineated by the period from Hellenic thought to Kant<sup>18,27</sup>, is an intrinsic aspect of human dignity that must be respected<sup>27</sup>.

Thus, on the plane of existence, respect for individual autonomy is expressed by a manifestation of will directed at a situation that is well understood by the individual who makes the decision<sup>15</sup>. In health care, respect for autonomy is formalized through instruments such as informed consent (IC) and advanced directives<sup>27</sup>, while free and informed consent forms (FICF) are an essential part of medical research. When it comes to minors or the disabled, consent should be sought in accordance with their capacity to understand<sup>28</sup>.

It is important to emphasize that in this context, the limitations of respect for autonomy in relation to decision-making processes are disparate<sup>29-33</sup>, especially in terms of: a) asymmetry in the relationship between health professionals (holders of knowledge) and patients (disease carriers) is often evident in the clinical encounter, in which the doctor's authority, although legally and ethically recognized, is to some extent a threat to the self-determination of the subject; b) the inherent conflicts established in the wake of principlist bioethics, in which the clash of principles – respect for autonomy, beneficence, non-maleficence and justice – used to solve a dilemma can lead to a reduction in the importance of autonomy in a given situation.

Taking the principle of respect for autonomy (PRA) as a guide, the central points of the decision-making process will be discussed below: *what* is to be decided (the theme); *who* will make the decision; *how* it will be decided.

### Conversations about the end of life

The term “human finitude” can be conceived as a universal feature of the existential condition of *Homo sapiens*, which is linked to the term “vulnerability” which comes from the Latin *vulnus*, meaning “wounded”<sup>5</sup>. In fact, every human being can be injured, fall ill and suffer, so that disease is a major source of the human perception of finitude<sup>34</sup>.

The current phenomenon of population aging has contributed to an increase in chronic diseases, which usually require prolonged treatment and can result in long – and painful – process of dying. This raises important issues both for the scope of individual health care and public health<sup>3</sup>, which has resulted in the involvement of various parties – the sick and their families, health professionals, lawyers,

philosophers, theologians, administrators and/or public officials, among others – in discussions aimed at making decisions about the end of life<sup>30,35</sup>. This movement has been largely driven by actual case studies and works of fiction, especially in film, such as *The Barbarian Invasions*<sup>36</sup>, *The Sea Inside*<sup>37</sup>, *Million Dollar Baby*<sup>38</sup>, *My Life Without Me*<sup>39</sup>, *The Diving Bell and the Butterfly*<sup>40</sup>, *You Don't Know Jack*<sup>41</sup>, among others.

Life and art exhibit different conflicts about finitude and the dying process, including with regard to situations such as euthanasia, assisted suicide, palliative care, dysthanasia and therapeutic obstinacy<sup>42,43</sup>. In this context of borderline situations, where patients with incurable diseases find themselves at the end of life, decisions regarding the suspension (or otherwise) of therapeutic measures and advanced support – antibiotics, cardiopulmonary resuscitation, surgery, hemodialysis, blood transfusion, diagnostic interventions, monitoring of vital functions, nutrition and mechanical ventilation, to name just a few, must be discussed.

### Who makes the decisions?

The protagonist in decision-making in issues related to end of life may be the individual who is about to die, his legal representative, considered a substitute, or a health professional. In this process, which also includes the role of family, the ideal situation is that all the actors can engage in fruitful dialogue so that the decision can be taken in the best possible way. Below, the role of each actor is discussed.

#### *The individual in the process of dying*

In general, it may be considered that, in *case of conflict of interests and of rights, the right of self-determination has logical priority over the others in the context of decisions about the life and death of the owner of such right; that is, the person in question is the most qualified to assess and decide the course of his or her own life*<sup>44</sup>.

In this context, the cornerstone of a free decision-making process is respect for the autonomy of the individual. This means, in the context of health care, that competent adults have the right to accept – or reject – medical treatment. Indeed, according to Daulas Ribeiro<sup>45</sup>, from an ethical and legal point of view, human dignity has its place guaranteed in the Magna Carta – according to *which no one shall be subjected to inhuman or degrading treatment* – in Civil Health



Law (Law 8.080/1990), in the Charter of Health Users' Rights – Article 3, items X and XI, which provide that *the choice of place of death and the right to choose alternative treatment, if any, and to refuse the proposed treatment*<sup>46</sup> – as well as in professional ethical codes. Similarly, the Rights of Users of São Paulo State Health Services Law (Law 10,241/1999) provides, in Article 2, item XXIII: *the right to refuse painful or extraordinary treatments to try to prolong life*<sup>47</sup>.

If the individual in the process of dying is able to make free decisions, the acceptance of his or her wishes in relation to end of life care, including abbreviation of the process of dying – *euthanasia* – must be recognized as an ethical imperative; in other words, excellent reasons are required for that particular patient's decision not to be respected. It should be noted, however, that the fear of being accused of negligence or of being sued (at an administrative, civil, criminal and ethical and professional level), can lead health professionals, especially doctors, to decide to continue with treatment irrespective of the wishes of the individual and/or his or her legal guardian, resulting in therapeutic obstinacy that may constitute genuine torture for the patient<sup>48</sup>.

In the absence of full decision-making ability on the part of the individual – in the case, for example, of a patient in a coma<sup>49</sup> – it is possible to make use of advance directives of will, an instrument that guarantees the right of a person to decide in advance, both negatively or positively, about the healthcare that he or she may receive in the future. It is the expression of will, indicated in advance, based on the principle of respect for autonomy. In Brazil, Resolution 1,995 / 2012 of the Federal Medical Council (FMC)<sup>50</sup> provides for advance directives of will of the patient, establishing the same in Article 1, *as a set of wishes, previously and expressly manifested by the patient with regard to the care and treatment he or she wants or does not want to receive when he or she is unable to freely and autonomously express his or her will*. Therefore, in circumstances where the patient is unable to communicate and/or freely express his or her will, the doctor will consider the advance directives, which should be registered in the patient's medical records, when making decisions. If there are no advance directives, the decision-making process will depend on the participation of the legal representative.

### **The legal representative/substitute**

Given the patient's inability to answer for him or herself, a representative should be appointed who shall make decisions on his or her behalf. There

are certain requirements to be considered in such cases: a) the legal representative will have in view the best interests of the patient; b) the will of the patient should be known, in fact, or deduced from his values and beliefs; c) respect for the wishes previously expressed by the patient is essential<sup>27</sup>.

*Substitute decision makers* should adopt a position on behalf of patients who are unable to communicate their wishes, and can follow one of three basic models: a) *a legal substitute* – where decisions are made on behalf of the patient, assuming his or her wishes; b) *pure autonomy* - where, once a patient has previously expressed his will, in such circumstances it must be fully respected (advance directives); c) *the best interests of the patient* - when the welfare or benefit to the individual is considered<sup>27</sup>.

An important aspect of the *substitute decision maker* concerns the advance directive, an instrument that guarantees the right of an individual to choose his health care treatment in advance, and which allows his or her legal representative to indicate, in the future, should he or she ever become unable to make decisions about the end of his or her own life, the kind of treatment that he or she should - or should not - receive. This is the advance expression of will, also based on the PRA<sup>31,50</sup>.

### **The role of the family**

In making decisions on behalf of others, Sergio Rego et al<sup>11</sup> questioned whether the wishes of the family should take precedence over that of the patient, as the autonomy of a person is related to his or her capacity for self-determination, and not merely a signature on a consent form. The family often puts pressure on the doctor-patient relationship: in some cases, children and spouses, wishing not to worry or cause the suffering of the loved one, request that information about the actual state of the sick person is withheld from he or she, creating a situation in which bad news is dealt with by a conspiracy of silence. In such cases the health professional must identify the wishes of the sick patient and evaluate, based on the information available, whether revealing information about his state of health will do more harm than good, in a given situation<sup>51</sup>.

Indeed, in this situation too, the cornerstone of free decision-making is respect for the autonomy of the subject. In health care, this means that competent adults have the right to accept – or reject – diagnostic and therapeutic procedures. These aspects should also be taken into account when including the role of the family in decision-making.

### The health professional

The transformation of the relationship between the health professional and the patient in healthcare decision-making reflects the move from what it is known as paternalism – according to which it was up to the doctor to make choices on behalf of the best interests and benefit of the patient – to the recognition of the autonomy of the patient and the ethical pluralism that permeates this relationship. In fact, recent research<sup>52</sup> has shown that Brazilian doctors from a range of specialties consider it proper to acknowledge the wishes of the patient and respect and use those wishes in decision-making. When it comes to end of life care, the health professional should in general allow the patient or his legal representative, to make free decisions about his or her fate<sup>11,28</sup>.

No health care provider is required to use disproportionate treatments. In this respect, FMC Resolution 1,805/2006<sup>48</sup>, has moved the debate forward by regulating the limitation or the suspension of procedures that support the life of the patient in the terminal phase of an illness, provided that it strictly respects their will, and that the patient is offered the necessary pain relief<sup>2</sup>.

### Provisional summary

The patient (or his or her substitute(s)), the family, and health professionals must be involved in healthcare related decision-making in end of life issues. In many medical circumstances, the individual in the process of dying – the most important interested party – cannot freely communicate their wishes, and so his or her legal representatives and/or family (such order of priority is suggested in decision-making, if the patient is unable to choose and there are no advance directives) must take the leading role in the process. This process, in turn, must involve, in addition to theoretical aspects, a bioethically appropriate methodological procedure. The method proposed by Schramm in his work “Concerning bioethical methods for analyzing and solving moral dilemmas”<sup>53</sup>, in accordance with the considerations of Rego et al in “Bioethics for health professionals”<sup>11</sup> will be presented below.

### Decision-making: a “possible” path or method for the “resolution” of moral problems

The decision-making process can be discussed in the context of disparate disciplines, including, among others, management, psychology and computational neuroscience. The approach taken in this

text follows established bioethical knowledge, what Schramm<sup>53</sup> described as “possible” paths to resolve moral conflicts. The method of applying rational and impartial analysis to concrete problems, developed by the author based on the thoughts of Aristotle – more precisely the relationship between theoretical knowledge (knowledge of the truth) and practical knowledge (actions of individuals) – presupposes that decision-making must consider value systems and reasonable/prudent preferences. Schramm also highlights that practical Aristotelian knowledge is concerned with action according to a system of values, “rational” and “reasonable” preferences<sup>53</sup>. In “Nicomachean Ethics”<sup>54</sup>, Aristotle uses the concept of the “moral discernment” of agents when weighing consequences. Therefore the practical reason for essentially concerning oneself with an action which can be considered *moral* corresponds to the virtuous character of the citizen, as well as the praxis of this agent<sup>53,54</sup>.

Indeed, both theoretical (descriptive and understanding) and practical reason (applied) are indispensable tools of bioethics, in that the first allows assessment of the cognitive quality and logic of moral reasoning, while the second defines the moral quality of actions legitimized by such reasoning, by weighing the actual or likely consequences and by the morality of the agent<sup>11,49</sup>.

The approach begins with ethical questions: *How do I know* (cognitive question) whether an action is good or bad? *How do I decide* (pragmatic question) as a person or professional, in my community, what are the objectives of my action and what values and moral principles are available as a defense? In other words: *How can I show* (communication question) to another that my answers are right or wrong? These questions reveal the interdisciplinary nature of bioethics, and share the adverb “how”, which refers to the paths, that is, the methods that can be used to answer them<sup>53</sup>:

*Because of this philosophers and scientists have believed for a long time (...) that the question of method is the only real question that must always be answered, so we can be sure (...) that we are in on the right path and that this certainty can be accepted by any rational being who understands what we want to say and understands the situation at hand*<sup>55</sup>.

Therefore, as theoretical bioethical tools, the rationality and reasonableness of arguments, which, being classified as rational, must be clear about the terms being used, as well as their limits and scope. They should also relate in an understandable way

premises with the reasoning and the conclusion of the argument, ensuring that all participants have access to the communication of the moral question presented<sup>49</sup>.

As for the practical reason, the tools available to bioethics consist, according to Schramm, of<sup>53</sup>:

- 1) *moral intuition*, to be used at the beginning of moral reasoning, a pre-critical state of analysis that can detect counterintuitive conclusions, which should be reassessed later, once identified. It should be used with discretion, and critically;
- 2) *exemplification* of facts and concrete situations as a form of argument, which often allows arguments to be streamlined;
- 3) *the use of analogies* in order to clarify the problem at hand, facilitating investigation of the arguments, rejecting or strengthening them as choices. It is important to analyze the use of analogies in a rational and critical manner, bearing in mind the limits of the analogy and the particular case under consideration;
- 4) *the slippery slope argument* widely used in unprecedented situations, and aimed at the possible harm and negative consequences of the action;
- 5) *the “devil’s advocate” role*, which provides the imaginary debate of the speaker him or herself, assuming the role of neutral spectator in an attempt to refute the patient’s initial arguments and thus strengthen ethical reflection;
- 6) *the search for compromise*, which aims to negotiate, for each conflict situation, a diplomatic and peaceful solution wherever possible. Its use should

be critically evaluated, as it can threaten the rational strength (communicative) of the argument.

The use of practical reason as an ethical tool is linked to the nature of analyzing problems through bioethics, including issues of birth, of living and dying – especially this last point, which is the focus of this article. Such issues are present in all areas of individual and collective life, and attract the interest of both experts and non-experts, as they can affect society as a whole.

## Final considerations

From bioethical reflection and debate on the issue of decision-making with respect to the advances of biotechnology in health sciences, one can choose from a number of adoptable positions regarding end of life, such as palliative care, intensive care, the refusal/suspension/non-imposition of unnecessary treatments, or the request for a “good death” (euthanasia), among others.

The use of different criteria for end of life decision-making – a process that should involve the patient (or his or her substitute), family and health professionals – is possible in a context in which respect for autonomy, with all its nuances and limitations, takes precedence.

There is a clear need for future studies to be developed regarding the intersection between bioethics and other fields of knowledge, in order to better understand how health professionals and people (whether sick or healthy) and their families approach the end of life decision-making process.

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