

Position statement of ANCP and SBGG on shared decision-making in palliative care

Posicionamento da ANCP e SBGG sobre tomada de decisão compartilhada em cuidados paliativos

Posicionamiento de la ANCP y SBGG sobre la toma de decisiones compartida en cuidados paliativos

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Abstract

Health care for patients with serious illnesses usually implies the need to make a large number of decisions, ranging from how information is shared to which diagnostic or therapeutic procedures will be adopted. The method of such decision-making has important implications from an individual and collective point of view and may contribute to either relieving or aggravating suffering. In this consensus document, the Bioethics Committee of the Brazilian National Academy of Palliative Care (ANCP) and the Permanent Committee on Palliative Care of the Brazilian Geriatrics and Gerontology Society (SBGG) adopt the principles of compassionate listening proposed by Saunders, of the nature of suffering proposed by Cassel, of dignity-preserving care proposed by Chochinov, and of cultural humility as a starting point for the construction of an official position of ANCP and SBGG on shared decision-making in palliative care. The position statement posits that, unlike paternalistic and consumerist models, the decision-making process in the sphere of palliative care must follow the mutualistic model of shared decision, where decisions are built based on dialogue between healthcare professionals and patients/family. The document sets forth the assumptions of this process, the limits of autonomy of patients/family and healthcare professionals and the distinction between futile and potentially inappropriate treatments, besides ratifying its incompatibility with any forms of coercion and conflict of interest foreign to the best interests of patients.

Palliative Care; Shared Decision Making; Consensus Development Conference

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The health care of patients with serious illnesses usually implies the need to make a large number of decisions, ranging from the way information is shared to which diagnostic or therapeutic procedures will be adopted ¹. Making a decision in the field of health care involves, as in other spheres of life, choosing one path over a variety of alternative paths. Many decisions can be easily reviewed and changed, such as when we discover that a particular drug has not achieved its intended goals and can be discontinued without causing serious or irreversible consequences. Other decisions have outcomes that cannot be reversed, such as when a patient dies.

It is reasonable to say that, generally speaking, those involved in such decision-making processes have the best of intentions and want to “get it right”, that is, to make the best decision possible at that specific time. However, this does not mean that some of the decisions to be taken do not involve conflicts stemming from different points of view among healthcare professionals, as well as those of patients and their loved ones, about what the “best choice” might be.

The circumstances in which health-related decisions are made are quite complex and involve several factors, such as the prognosis related to the patient’s illness; the probabilities of different interventions achieving the desired goals; the chances of adverse events occurring; the cultural perspective of patients and their families, which includes their personal values and preferences, among others. Two points should be highlighted regarding these factors. The first involves the uncertainties inherent in the different clinical judgments described above and the different degrees of greater or lesser fluidity of the manifestations of care preferences by patients and families over time. The second is related to the fact that the list of elements described above is a simplification of complex elements in constant interaction, of which we are often not even fully aware. For example, it is quite common for healthcare professionals to mistakenly view their judgments as purely technical, when in fact they are merely using their own cultural and professional perspective as a benchmark against which others should be judged ². Other examples of elements that often unconsciously influence decision-making processes involve previous experiences with the health system, various prejudices and fears, as well as the particularities of the verbal and non-verbal communication process in place among all those involved ³.

Such complexity requires healthcare professionals to have a number of skills and attitudes that go far beyond technical knowledge related to prognosis and the probabilities of success or failure of a given intervention, and which involve multiple elements, such as emotional and relational skills and humility.

There are several possible starting points for the development of reflections and recommendations regarding the decision-making process, not only in palliative care but in all areas of health care ^{4,5,6,7}. In this text we start out from the perspective that Cicely Saunders, based on a lifetime dedicated to the care of critically ill patients, deemed essential for the practice of palliative care ^{8,9}. Below is an example of her teachings from an interview for the Education for Physicians on End-of-Life Care Project in 1999 ¹⁰.

“I’m often asked what is the first thing you really want to say to somebody going into medicine or moving into palliative care. What is the major commitment? And I’m sure the answer is simply, ‘Listen to your patients’. They will tell you. They will tell you what they need. They will tell you who they are and what they can achieve” ⁸.

This is by no means an isolated quote from the founder of palliative care, but certainly one of her greatest convictions, expressed repeatedly in her writings ⁹ and even cited as the very origin of the hospice movement ¹⁰.

This message should be seen as a guiding light in the often troubled seas of decision-making. They are in line with the arguments of Cassel ¹¹ and Chochinov ¹² that if we want to contribute to reducing the suffering of patients and their loved ones, and preserving their dignity, our first effort must be to seek to better understand the multiple sources and aspects of their suffering, as well as their views on approaches and contexts that enhance or threaten their sense of dignity. Careful listening is the starting point of any genuine effort aimed at reducing suffering and preserving dignity, and therefore should be recognized as one of the commandments of palliative care. Without it we run the risk of, despite our best intentions, resorting to interventions that end up increasing rather than reducing the suffering of patients and their families.

The kind of listening advocated by Cicely Saunders corresponds to what we today call compassionate or empathic listening ^{13,14} and requires a quality of presence marked by openness,

non-judgment and genuine interest in understanding what is happening with our patients and their loved ones ⁹.

Striving to listen to patients and their families in an empathic and compassionate way is a significant challenge that may be different from what most healthcare professionals learned in the formal and hidden curricula of their education ¹⁵. The professional-patient relationship still mainly follows a paternalistic model, based on the biomedical view, with a focus on disease and an assumption of vertical relations. According to this perspective, professionals are seen as “guardians” of their patients. Often, their technical knowledge embedded in so much certainty that it prevents them from actively listening to patients. Such certainty is sometimes permeated by moral judgment. In these circumstances, any disagreement expressed by patients or their families is shut out and viewed by healthcare professionals as denial or lack of understanding about what they deem most appropriate for the patient ¹⁶.

Although the paternalistic approach may offer comfort in different situations and is even preferred by some patients ¹⁶, it has important limitations when the decisions to be taken involve uncertainties and require judgment about the adequacy of the balance between risks and benefits ¹. In such situations, information about patients’ values, goals and preferences are absolutely key to understanding which approaches can actually contribute to reducing their suffering and defining the extent to which the implemented treatment can achieve its purposes.

However, it is very easy to fall into paternalistic behavior. This is manifested in subtleties of language that may not even be consciously grasped. Terms such as orthothanasia, dysthanasia, good death, disproportionate treatments, suffering and dignity may have different meanings for patients, relatives and professionals, even within palliative care programs. For these terms to make sense and be truly useful it is essential to clarify which perspective constitutes their point of reference, i.e., according to the values/goals of whom they refer to in a given context. Unfortunately, in the absence of this type of clarification, these terms can be used, albeit unconsciously, as veiled ways to impose the cultural point of view of healthcare professionals through technical language that is difficult for patients/family to understand. Indeed, many of the conflicts between healthcare professionals and patients or their families regarding decisions on whether or not to implement therapeutic limitation are due to genuine differences in cultural perspectives on the meaning of quality of life and dignified ¹⁷.

The first safeguard against these types of conflicts may involve learning and practicing cultural humility, which is an attitude of openness and authentic curiosity towards the points of view of patients and their loved ones ^{18,19}. One of the essential components of the practice of cultural humility requires healthcare professionals to critically reflect on how their own cultural perspective may be affecting their interaction with patients and their families ²⁰.

The problems related to paternalistic behavior do not mean that the solution to the difficulties of decision-making on the health of patients with serious diseases rests on what has been called the consumerist ¹⁶ or informational ²¹ model of healthcare professional-patient relationship. According to this model, healthcare professionals merely present the patient with all relevant information about the approaches available for their health problem, including their risks, costs, benefits and uncertainties, so that the patient may then choose the option that best suits him/her. The role of healthcare professionals in the consumerist/informational model can be compared to that of a waiter who offers a certain menu of options to his customers and limits himself to answering their questions and bringing them their orders.

It is interesting to note that this second form of professional-patient relationship is also fairly removed from the principle of compassionate listening, as it does not require any effort of understanding and genuine connection between healthcare professionals and patients/family. Therefore, such an approach may also often result in interventions that end up increasing rather than decreasing the suffering of patients and their loved ones. This frequently occurs because the patients themselves may not be totally sure of what they want ²¹ or about the web of elements that contribute to their suffering, and may request, for example, out of sheer desperation, interventions that do not meet their needs. Additionally, many patients may feel helpless and overwhelmed by the decisions that need to be made ²².

Given the intrinsic limitations of the paternalistic and consumerist models of relationship between healthcare professionals and patients/family, the shared decision-making model ²³, also called the mutualistic model ¹⁶, was proposed as an alternative. At its core is the development of a kind of

relationship between healthcare professionals, patients and their families, characterized by dialogue that leads to sufficient degrees of clarity about the decisions that need to be made, the existing options and their likely consequences, risks, benefits and uncertainties, and the values and preferences of patients related to such options¹. Based on this set of information, healthcare professionals, patients and family members engage together in a deliberative process to reach a consensus on the best course to follow, bearing in mind the technical possibilities and the preferences of patients²⁴. Within this model, neither the healthcare professionals nor the patients or their families are totally sure a priori of the best decision to make. This will be built through ongoing dialogue, authentic effort of mutual understanding and openness to reassess points of view and previous decisions. The role of healthcare professionals may go beyond the simple interpretation of the patient's values and goals and how they would be better served by specific therapeutic or diagnostic approaches, involving joint reflection on values and goals²¹. Therefore, it is essential to recognize the need for a high degree of self-surveillance and cultural humility so that, during the deliberation process, healthcare professionals do not adopt a veiled paternalistic behavior and end up imposing, even if unconsciously, their own cultural values disguised as an effort to consider the patients' values and preferences.

The shared decision model is considered a modern ethical imperative²⁵ and at its core are the principles of active listening and dialogue based on a solid foundation of cultural humility. More than a number of didactically described steps for negotiating care goals²⁶, it is about the quality of the relationship developed between healthcare professionals and patients, closely aligned with the principles of palliative care.

The practice of a supposed "palliative paternalism", where professionals are invested with the duty of convincing patients/family about a "palliative" care plan that does not effectively consider the values of patients/family, but merely the cultural perspective of professionals about their suffering, is incompatible with the principles of palliative care and unworthy of its name, and may even be often compared to a kind of disguised coercion. From a bioethical point of view, such an attitude is as wrong as that of professionals who impose invasive procedures, disregarding the values of their patients/relatives. Indeed, "palliative paternalism" and "curative paternalism" can be seen as mirror images of each other, sharing the lack of cultural humility to recognize the importance of striving to understand the persons being cared for, their sources of suffering and what constitutes dignified treatment from their perspective.

If we draw on the metaphor of end-of-life care as a journey, in the paternalistic point of view, healthcare professionals know the best way and must be followed without questioning; in the consumerist perspective, the professional provides a map containing all the possible ways and lets the patient choose the one that best suits him or her. In the mutualistic approach, in turn, based on shared decision, professionals and patients seek jointly to find the best possible way by examining maps, reflecting on possible obstacles and the mishaps of each one, and discussing what is most important for the patient along the way. This metaphor, besides contributing to the understanding of different models of decision-making in health care, is useful for showing that the choices made can and should be reassessed along the way according to the emergence of new types of ground and landscapes, as well as changes in the status and prospects of travelers.

Moreover, it is essential to recognize the existence of limits to autonomy for both healthcare professionals and patients/family, that the shared decision-making process necessarily takes place within this reality, and that such limits vary according to the clinical context specific to each situation and to the degree of certainty regarding the prognosis, effectiveness and risks associated with each intervention. For example, a patient or his/her family cannot force a healthcare professional to prescribe a treatment for which there is a high degree of certainty as to its ineffectiveness in achieving the agreed goal and a high risk of serious complications when there are effective and affordable alternatives to achieve the same goals with a lower risk of complications. Likewise, no healthcare professional can enforce the withdrawal of a widely available treatment for which there is a high degree of certainty about its effectiveness in achieving the agreed goal and a low probability of serious adverse events. However, most of the decisions that care professionals, patients and their families face related to end-of-life healthcare happen in more uncertain contexts, where the mutualistic process of shared decision is the best option to negotiate care goals and guide decision-making processes.

Within the context of decision-making in palliative care, special attention should be given to the concept of therapeutic futility, which must be considered a clear limit to the autonomy of all involved, healthcare professionals, patients and families, in that futile interventions in a strict sense should not be adopted. In 2015, a committee made up of members of five international intensive care societies proposed that the term futile intervention in the field of health care be restricted to situations in which there is no possibility of its physiological goal being achieved²⁷. The bioethicist Bernard Lo, in his book *Resolving Ethical Dilemmas: A Guide for Clinicians*²⁸ cites three situations of futile approaches in a strict sense that converge with this definition: (1) interventions that have no pathophysiological rational basis (e.g., using an antibiotic for which it is already known that the germ responsible for the patient's infection is resistant); (2) cardiac arrest due to refractory hypotension or hypoxemia; and (3) interventions that have previously failed (e.g., maintenance of cardiopulmonary resuscitation procedures after 30 minutes of adequately performed but unsuccessful maneuvers). This type of definition of futility in a strict sense is an intelligent solution to problems related to the previous use of this term in a broad sense, which required the specification of the perspective (e.g., patients vs. professionals) to which it referred to make any sense²⁹.

Situations in which a given intervention may achieve its desired goal but whose ethical basis is questionable were called "potentially inappropriate interventions" by the abovementioned committee. Such terminology aimed to highlight two important aspects related to this type of situation. First, that such judgments comprise a technical component and a personal value component. Additionally, the term "potentially" was chosen in order to express the fact that such judgments are necessarily preliminary and should be reconsidered before any decision is made²⁷. Although the term "potentially inappropriate intervention" was initially conceived for a context in which the patient/family desired a given treatment considered inappropriate by the healthcare team, it is important to recognize that it also applies to situations in which healthcare professionals recommended a given treatment which the patient/family considered inappropriate according to their values.

Therefore, shared decisions are decisions that are planned, developed and executed based on the clinical relationship that considers that no complex decision can be made without considering facts, values and duties. For the bioethicist Diego Gracia³⁰, (clinical) facts support values. If there is no clarity regarding the facts, there will be no way to clearly identify the values that need to be protected. And the main duty of healthcare professionals is to promote and protect values.

The perspective on shared decision-making described in this document is consistent with the bioethical framework proposed by Forte et al.⁵ in which a sequence of four steps guides the decision-making process regarding the care of severely ill patients. Step 1 relates to the ethics of accuracy, where the main focus is the development of an accurate diagnosis and probabilistic estimation (i.e., which includes a margin of uncertainty) of prognosis and chances of success of different therapeutic approaches based exclusively on technical aspects related to scientific knowledge. Step 2 was called the ethics of understanding and is based on empathic communication to learn about patients, their biography, sources of suffering, values, expectations, priorities and preferences. Step 3 was called the ethics of situational awareness and involves the design of a care plan by the healthcare team which takes into account the scientific evidence and the values of patients/families, without incurring on futile interventions and striving to identify potentially inappropriate treatments, in terms of both scientific evidence and the values of patients/families. The fourth and final step of this proposal was named ethics of deliberation and relates to a process in which professionals and patients/relatives seek to consensually define the goals of care and a therapeutic plan, based on the elements identified in the previous steps.

Additionally, it is essential to recognize the importance, from a bioethical point of view, of the healthcare decision-making processes taking place in a context that is free from coercion or the influence of conflicts of interest beyond the best interests of patients³¹. Although this is a well-established principle present in the codes of ethics of several healthcare professions, it is important to recognize that such conflicts of interest may manifest themselves in indirect ways, such as when healthcare professionals are pressured by public and private institutions to avoid the indication of certain treatments.

Finally, it is essential that healthcare professionals should know and be able to assess the four criteria that define a patient's competence to consent to the adoption of a healthcare intervention³²: (1) to understand relevant information about their health problem and the different approaches

available, including their potential risks and benefits; (2) to appreciate interpret their health situation and the likely consequences related to the different approaches available; (3) to be able to communicate their decision; and (4) to demonstrate the logical reasoning process involved in their decision making. For obvious reasons, consent to interventions by patients who do not meet these criteria is neither ethically nor legally valid, making it necessary to obtain consent from a representative with such competence.

Position statement of the Bioethics Committee of the Brazilian National Academy of Palliative Care and of the Permanent Commission on Palliative Care of the Brazilian Geriatrics and Gerontology Society

In view of the above, the Bioethics Committee of the Brazilian National Academy of Palliative Care (ANPC) and the Permanent Commission on Palliative Care of the Brazilian Geriatrics and Gerontology Society (SBGG) issue the following joint position statement:

(1) The decision-making process related to health in the sphere of palliative care must follow the mutualistic model of shared decision, in which decisions are developed from the dialogue between healthcare professionals and patients/family. This approach presupposes: (a) that patients/family have been informed, in a clear and accessible way, about diagnoses, prognosis, therapeutic possibilities and/or complementary diagnosis, the likely consequences related to each approach, including their risks, potential benefits and uncertainties; (b) that patients/family are able to understand the information described in the previous item; (c) that healthcare professionals have been able to listen empathetically to patients/family in order to better understand their sources of suffering, values and priorities; (d) that healthcare professionals are able, in partnership with patients/family, to integrate the values and priorities of patients with the different possibilities of management, in order to build a consensus on the decision to be taken.

(2) Healthcare professionals must be able to critically reflect on how their own cultural perspective influences their interaction with patients/family, as well as practice self-surveillance to avoid adopting a veiled paternalistic behavior and imposing their cultural perspective during the shared decision-making process. Such an effort requires recognizing that terms like suffering, dignity, orthothanasia, dysthanasia and disproportionate treatment always refer to a certain point of reference, and it is therefore essential to clarify whether the perspective that qualifies them concerns the cultural perspective of patients/family or of healthcare professionals. This is especially relevant when there are conflicts between healthcare professionals and patients/family, which are commonly motivated by divergences in the cultural perspectives of these actors.

(3) The shared decision-making process is an ongoing effort and should consider the possibility of therapeutic trial periods in which, for example, an intervention is carried out for a specified time, so that during this period it is possible to obtain greater clarity about the effects of the intervention and the extent to which it meets the care goals agreed with patients/family. Therefore, the decisions taken should, whenever possible, be subject to reassessment and change depending on the evolution of the patient's clinical condition and context changes.

(4) It is essential to acknowledge that there are limits to the autonomy of both patients/family and healthcare professionals which vary according to the clinical context and the degree of certainty related to the prognosis, effectiveness and risks associated with each intervention. The mutualistic process of shared decision-making is the appropriate strategy to agree on care goals that best meet the needs of patients/family within the limits of autonomy that permeate the relationships between them and healthcare professionals.

(5) Healthcare professionals must understand that futile interventions in a strict sense are those in which there is no possibility of their physiological goals being achieved. They must be able to distinguish them from potentially inappropriate interventions, recognizing that the latter involve not only technical elements, but also depend on individual values and are provisional judgments that must be revisited, discussed and reconsidered before leading to a specific decision.

(6) Healthcare professionals should not implement futile interventions in the strict sense described

above, even if for compassionate reasons at the pleading of patients/family. In these cases, professionals should firmly explain to patients/family the existing ethical impediment in this regard, as well as their ongoing commitment to providing the best possible care to the patient.

(7) Healthcare professionals should not unilaterally adopt behaviors related to the suspension or non-introduction of life-prolonging treatments without the informed consent of patients or their legal representatives and without being totally sure that such behaviors are in line with the previously established values and care goals of patients/family.

(8) Shared decision-making processes are not compatible with any forms of coercion and must not be influenced by conflicts of interest foreign to the best interests of patients. In order to avoid indirect conflicts of interest from influencing the shared decision-making process, there must be institutional mechanisms in place that prevent the punishment or reward of healthcare professionals depending on the type of intervention that they might indicate.

Contributors

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Resumo

Os cuidados de saúde com pacientes portadores de doenças graves usualmente implicam a necessidade de tomada de um grande número de decisões, envolvendo desde a forma como a informação é compartilhada até quais procedimentos diagnósticos ou terapêuticos serão adotados. A maneira como tais decisões são tomadas têm importantes implicações do ponto de vista individual e coletivo, podendo contribuir tanto para o alívio como para o agravamento do sofrimento. No presente documento de consenso, o Comitê de Bioética da Academia Nacional de Cuidados Paliativos (ANCP) e a Comissão Permanente de Cuidados Paliativos da Sociedade Brasileira de Geriatria e Gerontologia (SBGG) adotam os princípios da escuta compassiva proposta por Saunders, da natureza do sofrimento proposto por Cassel, dos cuidados preservadores da dignidade propostos por Chochinov e da humildade cultural como ponto de partida para a construção de um posicionamento oficial da ANCP e SBGG acerca do processo de tomada de decisão compartilhada em cuidados paliativos. O posicionamento estabelece que, em contraposição aos modelos paternalistas e consumistas, o processo de tomada de decisão no âmbito dos cuidados paliativos deve seguir o modelo mutualista de decisão compartilhada, no qual as decisões são construídas a partir do diálogo entre profissionais de saúde e pacientes/familiares. O documento estabelece os pressupostos deste processo, os limites da autonomia de pacientes/familiares e profissionais de saúde, a distinção entre tratamentos fúteis e potencialmente inapropriados, bem como ratifica sua incompatibilidade com quaisquer formas de coerção e conflitos de interesse alheios ao melhor interesse dos pacientes.

Cuidados Paliativos; Tomada de Decisões Compartilhada; Conferência de Consenso

Resumen

Los cuidados de salud de pacientes portadores de enfermedades graves usualmente implican la necesidad de tomar un gran número de decisiones, que abarcan desde cómo se comparte la información hasta qué procedimientos diagnósticos o terapéuticos se adoptarán. La forma en que se toman tales decisiones tiene importantes implicaciones desde el punto de vista individual y colectivo, y puede contribuir tanto a aliviar como a agravar el sufrimiento. En el presente documento de consenso, el Comité de Bioética de la Academia Nacional de Cuidados Paliativos (ANCP) y la Comisión Permanente de Cuidados Paliativos de la Sociedad Brasileña de Geriatria y Gerontología (SBGG) adoptan los principios de la escucha compasiva propuesta por Saunders; de la naturaleza del sufrimiento propuesta por Cassel, de los cuidados preservadores de la dignidad propuestos por Chochinov y de la humildad cultural como punto de partida para la construcción de un posicionamiento oficial de la ANCP y SBGG sobre el proceso de toma de decisiones compartidas en cuidados paliativos. El posicionamiento establece que, en contraposición a los modelos paternalistas y consumistas, el proceso de toma de decisiones en el ámbito de los cuidados paliativos debe seguir el modelo mutualista de decisión compartida, donde las decisiones son construídas a partir del diálogo entre los profesionales de salud y los pacientes/familiares. El documento establece los supuestos de este proceso, los límites de la autonomía de los pacientes/familiares y de los profesionales de la salud, la distinción entre los tratamientos inútiles y los potencialmente inapropiados, así como ratifica su incompatibilidad con cualquier forma de coerción y los conflictos de intereses distintos del interés superior de los pacientes.

Cuidados Paliativos; Toma de Decisiones Conjunta; Conferencia de Consenso

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