

# Hospital bioethics committees: importance, operation and difficulties in implementation

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#### **Abstract**

Created in the 1960s, hospital bioethics committees help solve ethical health conflicts, ensuring the protection of the patients' human dignity. The aim of this article is to investigate the importance and operation of such committees in supporting patients, family members, hospital staff and health institutions in the face of bioethical challenges. A systematic literature review was carried out in the SciELO and PubMed databases between January and March 2021. The review showed the importance of hospital bioethics committees for the protection of human rights, through their support for autonomy and shared decision making in health issues, which can transform local corporate culture. The establishment and mandatory nature of ethics committees vary according to the country, with no established international standards. In Brazil, the absence of legal regulation is due to the lack of knowledge on the subject. This study aims to contribute to the advancement of regulations of hospital bioethics committees in the country.

Keywords: Bioethics. Ethics committees. Vulnerable populations.

#### Resumo

#### Comitês de bioética hospitalar: importância, funcionamento e dificuldades de implementação

Criados na década de 1960, os comitês de bioética hospitalar auxiliam na resolução de conflitos morais do campo da saúde, garantindo a preservação da dignidade e da humanidade dos pacientes. O objetivo deste artigo é verificar a importância e o funcionamento dos comitês como instrumentos de suporte a pacientes, familiares, profissionais e instituições de saúde diante dos desafios da bioética. Realizou-se revisão sistemática a partir das bases SciELO e PubMed entre janeiro e março de 2021. Verificou-se a importância dos comitês para a preservação dos direitos humanos, mediante apoio à autonomia e à decisão compartilhada nas questões de saúde, o que pode transformar a cultura corporativa local. A criação e obrigatoriedade dos comitês variam conforme o país, não havendo padronização internacional. No Brasil, a ausência de lei regulatória deve-se ao pouco conhecimento sobre o tema. Espera-se que este trabalho contribua para o avanço das regulações dos comitês de bioética hospitalar no país.

Palavras-chave: Bioética. Comissão de ética. Populações vulneráveis.

#### Resumen

### Comités de bioética hospitalaria: importancia, funcionamiento y dificultades de implementación

Creados en la década de 1960, los comités de bioética hospitalaria ayudan a resolver los conflictos morales en el campo de la salud, asegurando la preservación de la dignidad y humanidad de los pacientes. Este artículo propone verificar la importancia y funcionamiento de los comités como instrumentos de apoyo a pacientes, familiares, profesionales e instituciones de salud ante los desafíos bioéticos. Se realizó una revisión sistemática en las bases de datos SciELO y PubMed entre enero y marzo de 2021. Los comités son importantes para la preservación de los derechos humanos, a través del apoyo a la autonomía y la decisión compartida en salud, que puede transformar la cultura corporativa local. Su creación y obligatoriedad varía según el país, sin estandarización internacional. En Brasil, la ausencia de una ley reguladora se debe al desconocimiento sobre el tema. Se espera que este trabajo contribuya al avance de la normativa de los comités de bioética hospitalaria en el país.

Palabras clave: Bioética. Comités de ética. Poblaciones vulnerables.

The authors declare no conflict of interest.

"Bioethics" is defined as the systematic study of the moral dimensions (...) of the life sciences and health care <sup>1</sup>. The field of bioethics emerged in the analysis and study of health-related moral conflicts ranging from decision making in care about ethical dilemmas in medicine and biology <sup>2</sup> – arising from scientific and technological advances in health care and the ethical limits of their application <sup>3</sup> – to environmental, social and cultural issues relevant to human life <sup>4</sup>.

In the 1970s, bioethics' moral reflection on scientific and technological advances in the contemporary world focused on four pressing "bioproblems": the diseases that affected mainly the poor around the world; hunger; the dramatic demographic growth; and environmental destruction<sup>5</sup>. The concept of global bioethics – which considers that a global survival that protects human dignity is essential for scientific and technological development – allowed an in-depth reflection on the four "bioproblems" to be developed in the following decades<sup>4</sup>.

In the 1980s, bioethics was marked by a physician-patient reductionism. The *principlism* of Beauchamp and Childress, as it is currently called, was that period's main theoretical framework and applied worldwide. The third phase of bioethical thinking, which took place in the 1990s, was mainly characterized by the emerging criticisms of the Beauchamp and Childress model of the principles of biomedical ethics, in terms of both its theoretical framework and the limits of its applicability in different contexts, as in the provision of health services <sup>6</sup>.

Since the 2000s, alternatives to the Beauchamp and Childress theoretical model were proposed, including the first Latin American models <sup>6</sup>. These considered social injustices when examining ethical conflicts in healthcare, as well as institutional interests related to research and uses of technology, among others <sup>7</sup>.

In 2005, the United Nations Educational, Scientific and Cultural Organization (Unesco) adopted the Universal Declaration on Bioethics and Human Rights<sup>8</sup>, which legitimized internationally the theses proposed in Latin American bioethical models. Bioethical principles thus began to recognize and address vulnerabilities, with a focus on a fair distribution of the benefits of science,

environmental conservation and government and corporate social responsibility.

Bioethics based on human rights proposes that their aim is to promote human dignity, in order to allow all to fully develop their personal capacities? In the context of health care, safeguarding human rights should be a central concern in fighting diseases, thus ensuring dignity to people with vulnerabilities and illnesses and recognizing the diversity of approaches and possibilities of resolution.

Hospital bioethics committees offer support and protection to patients, their families, caregivers and other health professionals. These committees are spaces for dialogue in hospitals and other health institutions, promoting and improving the quality of health services and decision making and aiming to guarantee the respect for fundamental individual freedoms. Although no international standard bioethics committees exists, they play an important role in promoting bioethical reflections and a more horizontal relationship between the people involved, due to its multidisciplinary composition<sup>8</sup>.

Committee implementation varies according to the peculiarities of each country, and they can be created by the State or independently by the health institutions <sup>10</sup>. Hospital bioethics committees are mainly focused on educational, normative and consultative (on bioethical dilemmas) goals, whose fulfillment should be based on guaranteeing the respect for human dignity <sup>11</sup>.

Despite having been implemented in the United States since the 1960s, bioethics committees are still not mandatory in Brazilian hospitals and other health institutions. It was only in 1993 that the first Bioethics Committee was founded in Brazil at the Hospital de Clínicas of Porto Alegre. Since 1996, other Brazilian hospitals, especially large ones or those linked to medical education institutions, started to create bioethics committees <sup>12</sup>. Due to the lack of regulations, in addition to social, economic and cultural factors, there is no information on the current number of hospital bioethics committees in Brazil, neither on how they operate <sup>13</sup>.

In 2018, the National Network of Bioethics Committees (Rede) was created to survey and share knowledge and experiences regarding bioethical topics and bioethics committees. This network is not formalized yet and its 43 members, who come from nine states and the Federal District, maintain intense communication through a group chat created in the WhatsApp application. This group provides a space to share experiences and matters of common interest.

Understanding hospital bioethics committees as an advisory tool in the resolution of moral dilemmas involving health and life, the aim of this article is to show their importance and operation. The first section surveys of the history of the committees; the second section presents a systematic review of the importance of their implementation and operation; finally, we conclude with some considerations about the difficulties faced in their implementation in the country.

# History of bioethics committees in Brazil and around the world

Since the second half of the 20th century, scientific and technological advances in health services have raised moral issues that eventually led to the creation of committees within hospitals to advise on moral and ethical decisions in complex cases. The creation of the "God Committee" in the 1960s in the United States was the first report of the existence of a bioethics committee. Its role was to select the kidney patients who would receive dialysis treatment at a Seattle hospital, which had only a few dialysis machines available at the time <sup>13</sup>.

In 1976, aiming to ascertain the health conditions of a patient in a permanent coma, the New Jersey Supreme Court ordered the hospital where she was admitted to establish an ethics committee. The Court's decision was a milestone in the history of bioethics committees <sup>13</sup>.

In the early 1980s in the United States, a court case involving a baby born with malformations required the assistance of a hospital bioethics committee. Debates on the subject gained much importance, resulting in a significant increase in the number of hospital bioethics committees in the country – in 1982, only 1% of hospitals had ethics committees; by 1987 the percentage rose to 60%; and, in 1998, it had already reached 90%. However, despite the establishment of committees, their legal and institutional regulation still lacked homogeneity <sup>13</sup>.

In Europe, the European Convention on Human Rights and Biomedicine, which opened for signature in the 1990s, contributed to establishing common principles for the protection of the dignity of human beings within the field of biomedicine. The establishment and operation of European committees vary according to the country. Italy, for example, has a clinical ethics committee at the national level. Spain, in turn, is in the paradoxical situation of being one of the continent's most advanced countries in terms of advance directives of will and at the same time having few committees established, since these are not established at the national level. 14.

In Latin America, committees vary in how they are established and in their function. In Mexico, for example, a government commission supports their operation in hospitals, which promotes a focus on protecting human dignity and favors the development of a bioethical culture within the Mexican State <sup>15</sup>.

Colombia, despite having a national resolution regulating ethics committees since 1991 (Resolution No. 13,437), did not establish a standard for them. Hence the great diversity observed in their structure, function and operation, as well as in their names, such as Comité de Ética Hospitalaria (Hospital Ethics Committee) and Comité de Bioética (Bioethics Committee) <sup>16</sup>. Chilean committees were also established by the government, which started their implementation in 1994 <sup>17</sup>.

Since 1997 in Argentina, after a law enacted in 1996 <sup>18</sup>, all public hospitals were required to have a hospital ethics committee for advisory, research, instruction and supervision purposes regarding ethical issues related to the practice of hospital medicine <sup>19</sup>. The country currently faces the challenge of promoting bioethical responsibility in a context of technological and scientific advances in medicine, recognizing and respecting human dignity, human rights and fundamental freedoms.

In 2006, Unesco published an international guide on the establishment and operation of bioethics committees that classifies them into four categories. The guide aims to provide guidance to people regarding moral conflicts and improve their decision making capacity to improve the quality of health care. Furthermore, it emphasizes that these committees

should be established to help promote respect for human dignity <sup>20</sup>. However, several countries are yet to follow the recommendation, leaving health institutions to decide whether or not to implement them, as in the case of Brazil.

In 1993, the Hospital das Clínicas of Porto Alegre created the first Hospital Bioethics Committee, followed by the Hospital das Clínicas of the School of Medicine of the University of São Paulo and the National Cancer Institute, in Rio de Janeiro – all public hospitals <sup>12,13</sup>. Other committees exist in the country currently, such as in the Grupo Hospitalar Conceição, in Porto Alegre, RS (CBH-GHC), and in the Hospital de Apoio, in the Federal District (CBH-HAB).

Regarding bioethics committees in children's hospitals, only two are reported: in the Hospital Infantil Joana Gusmão, a public state hospital in Santa Catarina, and in the Pequeno Príncipe, a private hospital in Paraná<sup>21</sup>.

CBH-GHC was established in 2003 and twelve years later it drew up the *Charter of Rights of Patients of the Hospital Grupo Conceição*, the first of its kind in Brazil. The document was widely disseminated and, due to its simple and accessible language, remains an important guidance document for patients, their families and hospital professionals.

The charter's concepts of patient safety and protection are aligned with ethical values such as self-determination, informed consent, advance directives of will, patient representative, palliative care and vulnerable groups. It was later adapted into Bill No. 5,559/2016 <sup>22</sup> and filed with the Chamber of Deputies as an instrument for patient protection.

The CBH-HAB, the first HBC of the Federal District's Health Secretariat, was officially established on June 6, 2018. CBH-HAB's initial composition, formed through an open invitation sent by e-mail to the hospital staff, including all civil servants and volunteers, was multidisciplinary and covered all the hospital's areas. The committee was also composed of civil society's representatives <sup>23</sup>. In addition, the CBH-HAB also has a Patients' Charter of Rights adapted from the CBH-GHC's <sup>24</sup>.

Established almost three years ago, the CBH-HAB follows its own procedural rules and its purposes include making recommendations and performing educational actions aimed at patients and professionals, such as publishing educational booklets and posts on social media, holding lectures and conversation circles in team meetings. Moreover, CBH-HAB received bioethical inquiries and issued opinions requested in person and online by staff members. Finally, the committee maintained its activities even during the covid-19 pandemic.

The National Network of Bioethics Committees in Brazil – created on December 16, 2018, in the wake of the RedBioética Unesco Congress, held in 2018 in Brasília/DF – is currently composed of 43 members from nine states and the Federal District. Its goal is to bring together people who participate in committees or bioethics study centers in the country, and it holds the potential to promote changes and bioethical social actions, in addition to encouraging the establishment of other committees.

#### Method

This is a qualitative, exploratory and descriptive study that adopted a systematic review analysis technique for data collection. Searches were made on the SciELO and PubMed databases between January and March 2021 using the search queries "comitê de bioética" and "bioethics committees."

Articles in Portuguese and English describing hospital bioethics committees were included in the study, even when the committees were established under different names, as in the case of Europe, where they are called clinical ethics committees. The articles reviewed were published in the last 10 years. Articles excluded were those focusing on specific opinions of bioethics or clinical ethics committees, as well as on research ethics or bioethics committees, animal research bioethics committees, editorials, books, documents, clinical trials and other topics outside the scope of this study, published either in journals or in other publications.

#### **Results**

In total, 112 abstracts were found using the search query "comitê de bioética" in the SciELO

database, of which only five met our selection criteria for analysis. The query "bioethics committees" returned no results. In PubMed, 9 articles were found using the query "comitê de bioética" and 174 articles using the query "bioethics committees," four of which met our selection criteria and were included in the study.

Of the 9 articles selected, four dealt with the importance of committees, three focused on

shared decision-making and person-centered care, and one addressed the organizational clinical ethics in institutional cultural change. The remaining five articles addressed the operation of committees; one focused on the operation of committees in the country, three on hospitals and the last was an integrative review of clinical approaches to the support of health professionals facing ethical dilemmas (Table 1).

Table 1. Selected articles

| Author(s)                           | Year of publication | Country          | Database | Topic      | Summary   |
|-------------------------------------|---------------------|------------------|----------|------------|---|
| Perin <sup>14</sup>                 | 2020                | Italy            | SciELO   | Importance | Clinical ethics committees must be implemented in health care institutions to promote a change in attitude and a commitment to place people as the central axis of health care in daily clinical practice. The decision making process must be inclusive, educational, respectful of cultural values and supportive of institutional efforts aimed at quality improvement and appropriate resource use.   |
| Rabadán,<br>Tripodoro <sup>19</sup> | 2017                | Argentina        | SciELO   | Importance | Bioethics committees must face the educational and consultative challenge of promoting ethical awareness in shared and democratic decision making through interdisciplinary, intersectional and intergenerational dialogue, encouraging the building of values by their members. The committee's normative role is altered and the need for judicial control is reduced, as decisions are made through a transparent process respectful of human rights and fundamental freedoms. |
| Pitskhelauri <sup>25</sup>          | 2018                | United<br>States | PubMed   | Importance | The Netherlands, Belgium, Italy, Norway and the United Kingdom increasingly use clinical ethics committees to address new ethical dilemmas, strengthening the trend towards shared responsibilities based on patients' autonomy, plurality, rights and dignity in decision-making, in a shift away from the physician's single obligation in this process.  |
| Moon <sup>26</sup>                  | 2019                | United<br>States | PubMed   | Operation  | Institutional ethics committees are important in the education of health professionals, staff members and patients, and committee members require continuing training, allowing the development and review of institutional policies related to ethical issues in patient care, conforming to the principles of fairness and confidentiality.   |

continues...

Table 1. Continuation

| Author(s)  | Year of publication | Country   | Database | Topic      | Summary   |
|--|---------------------|-----------|----------|------------|---|
| Oliveira,<br>Oliveira and<br>Martins <sup>21</sup>                             | 2017                | Brazil    | SciELO   | Operation  | The article describes the experience of the bioethics committee in a Brazilian state public hospital and argues for the importance of encouraging the creation of such forums in the country's health institutions.   |
| Rasoal and collaborators <sup>27</sup>   | 2017                | Sweden    | PubMed   | Operation  | Integrative review of clinical approaches to support health care personnel in the face of ethically difficult situations. It concludes that there is no universal standard for the operation of committees in clinical practice.  |
| Carrillo-<br>González,<br>Lorduy-Gómez<br>and Muñoz-<br>Baldiris <sup>16</sup> | 2019                | Colombia  | SciELO   | Operation  | The study surveys bioethics committees in Colombia and finds that committees on the country's Atlantic coast have as their primary function education in ethical and bioethical issues, followed by specific activities of each committee, and that some do not have well-defined functions. The article advocates establishing standards to make them more effective in health institutions.                   |
| Ledesma and colaborators <sup>28</sup>   | 2015                | Argentina | SciELO   | Operation  | The article presents the experience of a public pediatric hospital's ethics committee in Buenos Aires created in 1994. Among the main considerations for satisfactorily meeting its demands, we highlight the reduction in formality for case presentation, parental consent form for discussing cases in the committee and the inclusion of the committee's recommendations in the patients' clinical history. |
| Woellert <sup>29</sup>   | 2019                | Germany   | PubMed   | Importance | Committees can assist in the implementation of organizational clinical ethics through consultancy, training and institutional policy development, making it an integral part of the corporate culture.  |

The main search difficulties we faced, and a possible research bias, is related to the lack of clarity in the concepts of ethics and bioethics and the lack of a standard nomenclature for hospital committees, as each country adopts their own concepts and nomenclatures.

Among the articles reviewed, the oldest is from 2015, and most are theoretical studies on bioethics committees describing their situation in particular countries or continents. All articles argue for their importance to decision making processes in health issues, as well as for their standardization and multidisciplinary composition. It is noteworthy

that only one Brazilian article was found in the consulted databases that suited our study's aim and method.

# Importance of Hospital Bioethics Committees

That fundamental freedoms and the dignity of each human being should be recognized is both indisputable and a challenge to the asymmetrical plural societies of our time, a task that requires maintaining the respect for and the dignity of each person <sup>11</sup>. In health care,

autonomy is recognized as an element inherent in human dignity, allowing the patient to participate in all decision making related to their condition. Several countries have instruments and laws aimed at guaranteeing the enjoyment of these rights; in Brazil, however, they have not yet been effectively applied <sup>30</sup>.

Health care should be centered on the human being, moving increasingly away from the paternalistic attitude of physicians and other health professionals, opening space for shared and democratic decision making <sup>14</sup>. Bioethics committees should take on this educational and consultative challenge of raising ethical awareness based on patients' autonomy and dignity in decision-making <sup>19,25</sup>.

People are, of course, more vulnerable when ill, a situation in which the value of dignity is even more important <sup>11</sup>. Vulnerability is a condition common to all human beings due to our finitude and frailty, but it extends beyond the mere biological condition. Human life is also vulnerable in social terms because of the dependence on other people's care and support at various moments in life, such as under the unfavorable circumstances of poverty, violence and unemployment <sup>31,32</sup>.

Continuing and outdated behaviors in former colonized countries, such as Brazil, manifest themselves especially in the violation of the person's right to health, such as in a culture of unilateral and paternalistic conducts in healthcare, or in civil society's lack of political engagement in the fight for rights, as well as in the country's huge social and cultural inequality 30,33.

From a bioethical perspective and considering the premise that all vulnerable people need protection, the patient should be viewed beyond their disease's biological and pathophysiological aspects. Situations that make people vulnerable should be considered in order to ensure their dignity and the protection of their rights. People receiving health care must have their rights to life, health, privacy, freedom, information and the right to not be discriminated against or subjected to inhuman and degrading treatment protected and guaranteed by the State <sup>34</sup>.

Health professional's routine also involves a series of individual, institutional, political, economic

and cultural factors, which might make them vulnerable, interfere with their behavior in daily situations and should be viewed from a bioethical perspective. A major difficulty health professionals have in guaranteeing human rights for patients is that they mistakenly believe that doing this would harm them, as the result of their action would not always be satisfactory to patients <sup>30</sup>.

Health managers also deal with a variety of issues that require organizational knowledge to ensure that concrete actions are taken to preserve and promote the health of patients and caregivers, such as family members, hospital staff and civil society representatives <sup>26</sup>.

Health institutions that shape their policies, programs and actions to meet the needs of patients improve service quality when patients participate in the decision-making process <sup>26</sup>.

Brazilian Congress is currently discussing Bill 5,559/2016 <sup>22</sup>, which addresses the rights of health services' patients – which differ from those of users of the Brazilian public Unified Health System (SUS). The Bill refers to the patient as a person who is in need of health care. Its importance lies in the fact that Brazilian legislation is currently not capable of guaranteeing the respect for patients' rights due to strong paternalism and to a culture of acceptance that hinders shared decision-making <sup>30</sup>.

In 2015, the Brazilian Federal Council of Medicine (CFM) recommended that bioethics committees should be established and maintained in health institutions according to criteria of relevance and number of staff members. These committees should be multidisciplinary, autonomous, consultative, educational and capable of meeting the healthcare institutions' bioethical needs. CFM Resolution No. 8/2015 35 specifies the following reasons for their creation, among others: Considering the many and relevant bioethical issues health institutions and professionals on a daily basis, (...) which go beyond the limits of medical ethics, signaling the expediency and need for bioethics committees to support medical decisions, (...) and that within the scope of Brazilian medical ethics physicians lack guidance on participation in bioethics committees 35.

In 2020, during the covid-19 pandemic, the Brazilian Bioethics Society (SBB) recommended

the establishment of bioethics committees in hospitals to assist in dealing with local particularities, complex decision-making and emotional care for staff members <sup>36</sup>.

Bioethics Committees are therefore capable of advising on the implementation of organizational clinical ethics, making it an integral part of the corporate culture <sup>34,37</sup>. A bioethical approach based on a hermeneutics of reality may be a tool for understanding the multiple relationships occurring within hospitals, including economic, legal and/or political aspects <sup>33</sup>.

# Operation of hospital bioethics committees

Committees are independent spaces located in hospitals, clinics and research institutions or laboratories. They are multi- and transdisciplinary in nature and aim to assist with patients' decision-making on health-related moral conflicts <sup>10,21</sup>.

HBCs offer a space for interdisciplinary dialogue and reflection in order to enable more horizontal relationships conducive to consensus building and to improved decision-making in health issues. For this reason, they provide an important assistance for hospital managers and professionals focused on guaranteeing respect for human rights <sup>17,38,39</sup>, and also help to reduce the number of lawsuits and have a positive impact on the microethics of care <sup>40</sup>.

Bioethics committees' implementation varies across countries according to two fundamental models: top-down and bottom-up. Top-down committees are established by initiative of the state or health institutions in certification processes <sup>10</sup>. Germany, Italy, Spain, the Netherlands and Mexico are some of the countries adopting a top-down approach <sup>15,40</sup>. Bottom-up committees, in turn, are established at the suggestion of and by staff members who identify the need for discussing ethical issues in the workplace, as in the case of Brazil <sup>10</sup>.

An integrative literature review concluded that there are no universal norms for the operation of clinical ethics committees, and its authors argue that a bottom-up approach can help health professionals assume greater ethical responsibility <sup>27</sup>.

Given the lack of a regulatory framework, many European countries spontaneously established clinical ethics committees based on multidisciplinary discussions and pluralism, representing an effective ethical consultation process aimed at implementing a global deliberative process <sup>14</sup>.

Colombia and Argentina adopted a top-down approach, although each with its own peculiarities. In Colombia, the committees' activities follow no universal norms, whereas in Argentina consultations were resolved satisfactorily within hospitals with less bureaucracy and easier access <sup>16,19</sup>.

In Brazil, there are no laws regulating bioethics committees and each institution creates its committee by assessing its needs and environment, establishing functions, duties, composition, conceptual approach, responsibility of members and limits to its action <sup>10,40</sup>.

The analysis of the environment helps to determine the committee's function, which can have a consultative, normative or educational nature. In its consultative role, committees aim to analyze and mediate cases, assisting patients, their representatives and health professionals in ethical conflicts, and their recommendations can be included in the patients' clinical history, generating greater visibility of and satisfaction with the committees' activities <sup>28</sup>. The normative function focuses on evaluating and contributing to institutional policies aimed at protecting the people involved <sup>28</sup>.

Finally, educational functions are broader and involve both the hospital staff and the community in addressing the ethical dimensions of health <sup>38</sup>. Continuing training based on the principles of justice and confidentiality is provided to health professionals, other staff members and patients. This can favor organizational clinical ethics by making it an integral part of corporate culture <sup>29</sup>.

Bioethics committees should have a multidisciplinary composition, including health professionals, lawyers, sociologists and philosophers, as well as civil society members, representing both users and non-users of healthcare services. Committees' implementation strategy and efficient operation may vary among health institutions and should integrate the different institutional and personal realities without conflicts of interest <sup>10,40,41</sup>.

In their basic operation, bioethics committees deal with alternative approaches to the solidary sharing of experiences, which may go beyond the normative, consultative or educational model <sup>40</sup>. Less formal procedures for presenting cases can favor resolution, as well as obtaining parental consent for discussing cases involving minors, if necessary <sup>28</sup>. The frequency and format of opinions also depend on the cases submitted to each committee.

# Difficulties in establishing committees in Brazil

The lack of academic research into bioethics committees and the heterogeneous nomenclatures in use can pose a first barrier to implementation by obscuring their importance and operation. Specifically in Brazil, the fact that there is no specific legislation regarding the patient reveals a paternalistic and obsolete culture <sup>30</sup>, in addition to the lack of regulation of the committees' implementation and operation. With no regulation at the national level, institutional and professional interests may interfere and, therefore, possibly harm the patients' dignity <sup>10,39,40</sup>.

Finally, the lack of institutional support – manifested mainly in the number of working hours health professionals have available for participating in a committee, the unilateral approach to implementation, the increase in bureaucratic procedures and the interference in the doctorpatient relationship – is another factor identified as a barrier to implementation <sup>10,39,40</sup>.

### Final considerations

Committees created in the 1960s can provide guidance on the proper care of vulnerable people, respecting their human rights, dignity,

autonomy and shared decision-making; furthermore, they help family members and health professionals and institutions to solve bioethical issues involving health and life. These horizontal and multidisciplinary spaces for dialogue may change corporate and institutional culture, affecting attitudes and giving rise to a patient-centered ethical culture.

Although there are no international standards for the operation of bioethics committees, some countries have regulated their activities in law. However, this is not the case in Brazil. Spontaneous and collaborative initiatives such as the Brazilian National Network of Hospital Committees can help in discussions and efforts to achieve greater homogeneity in their operation in the country, in addition to enabling the benefits to reach all people receiving health care.

Among the difficulties in establishing bioethics committees in Brazil, the most important are the lack of studies, which leads health teams and the population to lack knowledge about their existence and importance for advising on ethical issues; the absence of legislation on the establishment and regulation of hospital bioethics committees; and the self-interest of health institutions, private or public.

Given the important and urgent health problems that Brazil is facing and the scientific evidence of the benefits of bioethics committees, their implementation in health institutions is an urgent task.

Further studies should be carried out of topics such as emergency services, adult palliative care, children's palliative care, genetics and obstetrics/maternity, emergency services in case of major accidents, among others. These studies should consider the characteristics of health services and highlight the importance of hospital bioethics committees in advising decision-making and protecting human dignity.

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#### Participation of the authors

Mariana Calefi developed the structure of the article and prepared the introduction, history, method, results, discussion and final considerations. Rogério Amoretti carried out the literature review, developed the structure of the article and prepared the abstract, translations, history and final considerations.

**Received:** 6.1.2021 **Revised:** 9.28.2021 **Approved:** 10.21.2021