# Implementation of bioethics committees in Brazilian university hospitals: difficulties and viability

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#### Abstract

The objective of this article is to present and discuss the process of implementation and functioning of clinical bioethics committees in the hospital complex of a Brazilian public university, with four of its hospitals having these commissions in different structuring stages: a general hospital; a psychiatric hospital; a children's hospital and a maternity ward. For this, alternatives, difficulties, as well as the viability, are discussed for their implementation, in addition to practical recommendations in the form of steps, with accounts of experiences in Brazil and around the world. The aim of this report is to contribute to the bioethical reflection regarding the increasing ethical challenges arising from scientific developments in biomedicine. It is also the aim of this report to encourage the future development of bioethics committees in our country and the critical appraisal of this important item of ethical deliberation.

Key words: Bioethics. Clinical ethics committee. Institutional ethics.

#### Resumo

#### Implementação de comitês de bioética em hospitais universitários brasileiros: dificuldades e viabilidades

Este artigo objetiva apresentar e discutir o processo de implantação e funcionamento de comitês de bioética clínica no complexo hospitalar de uma universidade pública brasileira, na qual quatro de seus hospitais são dotados dessas comissões, em diferentes etapas de estruturação: um hospital geral, um psiquiátrico, um hospital infantil e uma maternidade. Para isso, são discutidos meios, dificuldades e viabilidade para sua implantação, além de recomendações práticas em forma de etapas, com relatos de experiências no Brasil e no mundo. Com o presente texto busca-se contribuir para a reflexão bioética sobre os crescentes desafios éticos decorrentes dos desenvolvimentos científicos da biomedicina, que se materializam na atenção em saúde nas instituições. Busca-se, ainda, fomentar um importante passo para o desenvolvimento de comitês de bioética em nosso país e a apreciação crítica desse importante dispositivo de deliberação ética. **Palavras-chave:** Bioética. Comitês de ética clínica. Ética institucional.

#### Resumen

#### Implementación de comités de bioética en hospitales universitarios brasileños: dificultades y viabilidades

El objetivo de este artículo es presentar y discutir el proceso de implantación y funcionamiento de comités de bioética clínica en el complejo hospitalario de una universidad pública brasileña, con cuatro de sus hospitales poseyendo dichos comités, en diferentes etapas de estructuración: un hospital general, uno psiquiátrico, un hospital infantil y un pabellón de maternidad. Para esto, son discutidos medios, dificultades y viabilidad para su implantación, además de recomendaciones prácticas en forma de etapas, con relatos de experiencias en Brasil y en el mundo. Con el presente relato se busca contribuir a la reflexión bioética sobre los crecientes desafíos éticos derivados de los desarrollos científicos de la biomedicina, que se materializan en la atención a la salud en las instituciones. Se busca también fomentar un importante capítulo del campo que es el futuro desarrollo de comités de bioética en nuestro país y la apreciación crítica de este importante dispositivo de deliberación ética.

Palabras-clave: Bioética. Comités de ética clínica. Ética institucional.

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The purpose of this article is to present and discuss the process of implementation and operation of clinical bioethics committees in the hospital complex of a Brazilian public university. Composed of several health units, four of their hospitals have these committees in different stages of structuring: a general hospital, a psychiatric, a children's hospital and a maternity.

The clinic or hospital bioethics committees, as they are called in Brazil, have been designed in the period 1960-1970, in the United States of America (USA), as a structure which had the function to assess the relevance of decisions regarding the treatment of individual patients and in particular, to determine when it was appropriate to stop treatment of artificial maintenance of life<sup>1</sup>, but without making the final decision. Initially designed to assist the decision making about the end of life, assessing whether the treatment in view of technical progress was adequate, reasonable or "ordinary" in a more ethical than technical analysis, as originally proposed by the pediatrician Karen Teel, committees were expanded. Recently, their activities also turned to the development of institutional policies and actions relating to clinical ethics education in healthcare facilities worldwide <sup>1,2</sup>.

The actions described in this paper are part of the extension project in the area of clinical bioethics, for the implantation and development of bioethics commissions in the University Hospitals complex in reference. The project is conducted within the graduate program in association with higher education in Bioethics, Applied Ethics and Public Health Institutions, sponsored jointly by the Federal University of Rio de Janeiro (UFRJ), Oswaldo Cruz Foundation (Fiocruz), University of the State of Rio de Janeiro (Uerj) and Federal Fluminense University (UFF), at post-doctoral level (PNPD-CAPES), and the Laboratory of Clinical Bioethics at the area of bioethics at the Institute for Studies in Public Health (IESC) of UFRJ. The report is based on the activities of the team members who have deployed and participate in the meetings of all committees, in order to promote their development and institutionalization.

The work is divided into three parts. In the first there are presented, based on national and international literature, the definition, origins, functions and composition of bioethics committees. In the second, we discuss the media, difficulties and feasibility for their implementation, with reports of experiences in Brazil and worldwide. In the third, it is presented and discussed the process of implantation and development committees based on this project experience. With the presentation of this report we seek to contribute to bioethical reflection on the ethical challenges arising from increasing scientific developments in biomedicine, which materialize in health care institutions. We also seek to foster an important chapter in the field: further development of bioethics committees in our country and critical appreciation of this important ethical deliberation device.

# Bioethics Committees: origins, functions and features

The '60s and '70s were marked by intense public debate and criticism turned not only to the issues around research ethics and abuses, but also to the ethical issues related to health care, especially for the intensive use of new technologies. The structuring of clinical bioethics committees and other instances of ethical deliberation and analysis, such as research ethics, in several countries, especially in the USA, was one of the expressions of such criticism, contributing to the institutionalization of bioethics in both health areas as for its academic consolidation <sup>2</sup>.

Thus, the origins of bioethics committees are back to the U.S., highlighting the paradigmatic judicial cases that mobilized public opinion because, on the one hand, of the gap between advances in health and the criteria for choosing beneficiaries; on the other, due to conflicts around the behavior shown in limited clinical cases. There was a question about the shortcomings of the system and the difficulties of the medical staff resolve clinical situations of ethical conflicts (Seattle Committee/USA, Quinlan, Baby Doe)<sup>2-7</sup>. These cases have in common differences between family and health care team responsible for decisions about medical procedures, which were mediated by judicial procedures.

The idea of a structure that could decide on conflict situations in individual patient care gained momentum with the judicial recommendation of these cases, but it was not fully developed: in 1983, only 1 % of hospitals had ethics committees on their boards, according to a study of the Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research <sup>1</sup>. Only at the end of the '80s its formalization became reality, generalizing almost all U.S. hospitals, with the support of organizations such as American Medical Association (AMA). Finally, with the Accreditation Manual for Hospitals, which took place in

1992, from the Joint Commission on Accreditation of Healthcare Organizations, it was established as a criterion for quality and condition of accreditation, the existence of ethical advisory services in the care process, changing the context of 1% of committees in hospitals, in 1983, to 60% in 1989 and 93 % next to 2000 <sup>8</sup>.

It is also considered a significant step forward for the implementation of Committees in other countries the adoption by Member States of Unesco, in 2005, of the Universal Declaration on Bioethics and Human Rights, which recommended the creation and support to committees, both to evaluate the relevant ethical, legal, scientific, and social problems that refers to research projects involving human beings like to give opinions on ethical problems in clinical settings<sup>9</sup>.

In this new context, there is increasing demand for training in bioethics and greater social penetration of clinical ethics. Studies show an increased acceptance by healthcare professionals of discussions on ethics <sup>10</sup>, especially those involving clinical cases of greater complexity. If in a first step the development of bioethics committees originated with the challenges posed by technical progress in medicine with their new standards of care in a context of cultural diversity <sup>4,11</sup>, currently the growing movement legalization of health and greater awareness of rights have constituted the driving force for such an opening. For Vasconcelos 12, excessive judicialization as arbiter of the relationship between users and the health care system has been a mistake in the quest for greater symmetry in this relationship. In the view of the author, access to justice, especially in view of large social inequalities, may mean extending citizenship and vulnerability reduction, however, making it rule may mean replacing a relationship with a careful attention to the belligerence, producing the so-called "defensive medicine" 12.

In health institutions, in short, the broader discussions of clinical cases of greater difficulty in terms of decision-making in situations of moral conflict have been performed on this new structure are the bioethics committees. This is the instance in which participating health professionals and other areas, as theologians, jurists and philosophers, as well as representatives of users and the community, which is multidisciplinary and multi-professional <sup>2,3</sup>. Its proposal is to establish itself as plural and dialogic space that values all actors in the search for solutions to conflicts in the health scenario.

Although the proposal is the flattening of the relations of present forces, Singer and colleagues  $^{\rm 13}$ 

have drawn attention to the danger of their consultants exceed the function of recommending courses of action and take the process of decision making as well as the professionals follow the recommendations without pondering them, in view of the fear of lawsuits.

Despite the potential dangers, bioethics committees have been advocated by many authors as a useful tool to facilitate decision-making in institutional settings by expanding the argument between those who face ethical challenges relating to the care of a patient <sup>14</sup>. Singer and colleagues <sup>13</sup>, in 1990, stated that consultation services would become even more important in the coming years due to technological progress, moral pluralism and legal interventions, further hindering the task of decision making. Alongside these, other aspects of care practice justify the creation of bioethics committees, such as the recognition of patient autonomy and religious beliefs of groups, besides the need to discuss ethical resource allocation available <sup>15</sup>.

In order to ethics consultation complies with the proposed objectives, different approaches are advocated: the Bioethics Committees, properly, and individual consultants. The American Society for Bioethics and Humanities (ASBH) proposes mixed model or formed by small teams, with the committee model as the most frequent one <sup>8</sup>. These models achieve their goals through three activities: 1) Coordination of education programs in ethics, including forming their committee members; 2) aid in the development of institutional policies that define the ethical position of the health unit before certain situations and; 3) consultation in individual cases, in which one seeks to identify potential conflicts and moral issues that the case raises <sup>4,5,13</sup>.

Singer and colleagues <sup>13</sup> have four models of clinical ethics consultation, with their advantages and disadvantages:

- a) pure model committee the user, who may be a family member or professional, presents the case to the committee and they discusses and makes their recommendations;
- b) committee member as a consultant the request is made to the committee that appoints one of its members to review the case. The analysis results are presented to the committee, which discusses them and makes recommendations;
- c) post fact analysis committee the request is made directly to the consultant who analyzes and makes recommendations. The case is further analyzed by a committee;

d) pure query template – the request is made directly to the consultant who analyzes and makes recommendations, without their further analysis by the committee.

In terms of advantages, *the pure model committee* provides greater institutional consensus and support for the recommendations. In turn, the *pure consultation model* provides faster and more efficient response. Models that combine the strategies of committee and individual consultant ensure broader discussion and greater control of decisions <sup>13</sup>. According to Ribas-Ribas <sup>8</sup>, authors such as La Puma and Toulmin, Siegler, and the working group ASBH concluded that should not be exclusive choice of any of these models, as each one of them is well applied to different situations.

Francisconi, Goldim and Lee <sup>5</sup> synthesize the discussion by saying that a Committee on Bioethics has triple function: educational, regulatory consultative, with evaluation and discussion of issues and moral dilemmas with origin in the practice and procedures within the institution, with a view to improving the service offered <sup>4</sup>. It is highlighted that the Bioethics Committee differs from other ethics committees which also operate in health institutions, such as the Committees of Ethics and Medical Deontology and Nursing, aimed at observation of the performance of professional duties of doctors and nurses. In addition, the Research Ethics Committees, which seek to assess the adequacy of the ethics research projects involving human subjects <sup>4</sup>.

# Implementation of bioethics committees: experiences in Brazil and in the world

In this section some concrete measures used for the deployment and development of bioethics committees, the problems most commonly involved, as well as brief assessment of its implementation in some countries and in Brazil will be presented and discussed. A study by Vollmann in 2010 <sup>16</sup> sought to demonstrate the importance of the deployment process of the committees, which in practice has been a complex process and even difficult, due to conflicts of interest and resistance to changes.

Studies on the deployment and operation of hospital bioethics committees have also been published in Europe and they have already sufficient time to permit evaluation of these experiments <sup>17</sup>. In practice of European countries like Germany, Italy, Netherlands and the countries being called "of transition" such as Georgia, Bulgaria and Croatia, the structures of bioethics committees, denominated in those countries of Clinical Ethics Consultation , were commonly implemented by official state initiative or institutional initiatives that run under the management processes of accreditation of health institutions <sup>17,18</sup>. The creation of ethics committees in Georgia exemplifies the process, which gained momentum in 2003, determined by national legislation, with the recommendation of the National Council on Bioethics, created in 2000<sup>19</sup>. In Netherlands <sup>18</sup>, the country with the longest tradition in this field, in 2005 the center for Ethics in Health Care advised the government to pay more attention to moral deliberation structurally among health professionals, a proposal for a permanent relationship between deliberation and institutional policy.

These deployment strategies and implementation of "top down" committees are defined by Vollmann <sup>16</sup> Schildmann <sup>14</sup> and as top-down approach. It means that structural initiatives are undertaken by management, collateral materials inputs and infrastructure, which can ensure the institutional point of view the actual creation of this innovation by the involvement of anyone who is in the highest decision-making position and capacity of greater regulation <sup>19</sup>.

Another strategy of implementation is called *bottom-up*, with the origin of the "bottom-up" initiative, i.e., part of employees who see the need for regular discussion on ethical issues that arise in the daily work. This approach has the advantage of from the work environment itself, which is a crucial aspect for the acceptance and the vitality of the committees in the institutional context <sup>16</sup>.

In Argentina <sup>20</sup>, pioneer of Latin America in the creation of ethics committees, there were two moments in the structuring of these instances. The first one, slower, resulted in the consolidation of many committees and in their transformation into reference centers whose structures, on the second time, obey the legal regulatory framework sanctioned in the 90s. Despite the regulation by of creation of National Law Ethics Committees of 1996 <sup>20</sup>, its growth was cluttered, without the support of the Ministry of health and in a context of privatization of the essential services.

According Luna and Bertomeu<sup>20</sup>, the emergence of the committees in the country was due to pressure than the legal recognition of a need. This created numerous problems, from those related to acceptability by professionals to the lack of differentiation as the functions, powers and different training required between clinical ethics committees and research ethics committees in the law. This process of creation was an exception only for hospitals, which, because of their own ethical dilemmas of their specialization, as a children's hospital and other care of AIDS patients, created their ethics committees before or in parallel with the laws.

In Brazil, in contrast, structuring of bioethics commissions occurs at the initiative of the health unit and not by national law or guideline that verses over its creation. There is little tradition in the formation of such structures in health facilities, as well as training and professional training in ethical issues. However, since the 90s there is change in this scenario and the first bioethics commissions are implemented, emphasizing the experiences of the Hospital das Clínicas de Porto Alegre (UFRS), the Programme of Support for Problems of Bioethics, 1993; Hospital São Lucas (PUCRS), <sup>4-6</sup> in 1997; Hospital das Clínicas de São Paulo (USP) - Cobi/HCFMUSP in 1996<sup>21</sup>; the National Cancer Institute, in Rio de Janeiro (ConBio), established in 1999<sup>22</sup>; and HUCFF-UFRJ in 2003 <sup>23</sup>.

Despite the shift in the framework for the creation of these bioethics commissions, there are few reports on the background and history of the committees in Brazil. However, changes have occurred in 2011 and 2012 and at least two committees published their experiments: the first was the case report on the establishment of the Bioethics Committee of the Hospital Infantil Joana Gusmão, in Florianópolis/SC, starting educational activities in 2010 and advisory activities and the creation in 2011. The creation occurred after sensitization of professionals (medical staff and employees of various services) on functions, composition and modus operandi; establishment of criteria for selection of members of a constitution and organizing core<sup>15</sup>. The second work <sup>24</sup> was the dissemination of research that sought to check the key successes and problems of the first three years of operation (2007-2009) of the Bioethics Committee of Hospital Universitário Santa Terezinha, of Universidade do Oeste de Santa Catarina (Joaçaba/SC) – are still rare considering the assessments, the latter modifies this perspective in Brazil.

Returning to the issue of top-down and bottom-up approaches, it is emphasized that these different realities of the institution must converge in order to obtain the proper implementation and effective development of the committee. Vollmann <sup>16</sup> proposes a model with character recommendation for the implementation and development of bioethics committees, that the practical point of view has proved very useful to those professionals who accept the challenge of implementing them in their institutions

A first point to note is that for the successful implementation of the commissions, the functions, powers, composition and limits of action need to be clearly defined. A second aspect is the confrontation of the objections that arise in practice by professionals, highlighting the lack of time claim; the vision of the committee as *something imposed by the administration*, especially if ordered by management very quickly due to the certification processes; the idea of *interference in the trust patient-doctor relation-ship*<sup>8,16</sup> or increase in the *bureaucratic burden*<sup>16,20</sup>.

In this sense, it is argued that ethical reflection and broad discussion promote the increase in the repertoire of action and greater ability to analyze the professionals because of the sharing of complex situations, and making work and actions more effective. Moreover, due to the sharing of responsibilities, the team itself can be a protective factor for the professional against illness and problems of burnout because of overloads arising from the nature of the work. This ultimately bring improvements to one aspect of the much neglected institution which, increasingly, is pointed out as essential in clinical practice in studies and experiences: communication, whether in clinical situations boundary among staff, patients and their families, and among the professionals <sup>25</sup>, providing improvements in assistance offered and in the workplace.

In his study, <sup>16</sup> Vollmann presents some practical recommendations, in the form of six stages, to help in the foundation and implementation committees, as well as recommendations are subject to changes and adaptations to reality, history and goals of the various institutions and committees.

In general, the first step of the deployment program <sup>16</sup> is facing the "administration" of the institution – understanding the context of the emergence of demand and if there is a formal request for founding committee. In foundation work is central to defining the rules and objectives of the committee, as well as hours worked in the workload of the staff, material resources and infrastructure that enable their implementation

Step 2 back to the early activities of a "coordinator" that seeks the imposition professionals who are interested in participating in the committee. This occurs through internal disclosure of objectives, establishment of a working group to discuss topics of interest to the community, including existing structures in the institution, as members of the professional ethics committee, research ethics etc. Step 3 turns to the "working group" with the formation of the permanent committee with members from different professional groups and the institution, and external members. It is important to establish the frequency of meetings, to favor the inclusion of the commission in the organizational flow and initiate reflection on the discussion method based on conceptual frameworks and principles of bioethics, observing, however, the style of each structure

Step 4 – "clinical bioethics committee" – is linked to the foundation itself, whose strategy can associate it with an event in which the institution may be presented and discussed and practical topics of local interest. From the institutional existence of the committee, by means of decrees appointing the members, it is important to establish deadline for their renewal, which may be two to three years, with a manageable number of participants. Furthermore, it is important to elaborate statutes governing procedures and rules, but not many details, not to restrict the daily work in the future. After the foundation, finally we come to step 5, in which there is the development of conceptual and communicative work. This means promoting regular talks on sensitive issues related to professional practice, stimulate discussion and even education and training to guide the decision making of professionals based in ethical reflection and argumentation aspects still missing in academic education.

Step 6 involves specialization of services, with the development of ethics consultation for clinical specialties, as problems in a committee can vary greatly from one specialist area to another. For this reason, it may be useful to adapt the configuration and working procedure for specialties such as psychiatry, pediatrics, intensive care medicine, with questions about the beginning and end of life, palliative care etc. Other important recommendations of this step are: building network with other committees; guaranteed confidentiality (discussion on security and confidentiality); scientific research on clinical bioethics committees and international cooperation for the exchange of experiences <sup>16</sup>.

## The creation of bioethics committees in a Brazilian public university

This section presents the case report regarding the implementation of bioethics committees in a Brazilian public university in four of its health units: a general hospital for adults, a children's hospital, and a psychiatric and maternity hospital, with very different characteristics and at different stages of development. The implementation of bioethics committees in these units occurred in the period 2010-2012, except for adult general hospital, which is earlier. For other units, the steps proposed in the project implementation were:

- Searching of the direction of the unit to expose the implementation committee project;
- Project exposure to the social body of the unit (usually in study centers or similar bodies activities), with time for discussion, the group aimed to raise awareness about the importance, functions and characteristics of bioethics committees;
- Identification, in collaboration with the leadership and interested professionals, the permanent members of the committee (it is recommended approximately 20 members, with multidisciplinary, including at least one participant who does not belong to the area of health);
- Establishment, by unit, of the frequency of meetings (except the children's hospital, which is fortnightly, other units have opted for monthly meetings);
- Establishment of the dynamics of the meetings, with maximum time duration of 60 to 90 minutes.

The dynamic proposal for the meetings was organized as follows:

- relevant news of the latest cases;
- case report by requesting professional opinion to the commission and other professionals directly involved in the care, exposing the "technical" aspects of an interdisciplinary approach (clinical state, legal, social, cultural, emotional and institutional status of the patient and family);
- identification of potential conflicts and moral issues that the case approaches. Discussion with the expansion of information and identification of possible courses of action to subsidize to ethical decision making by the team responsible. Preparation and presentation of arguments;
- record, through book, of the meetings.

#### **General Adult Hospital**

The foundation of this committee took place in July 2003 and sought to initially gather the various departments of the hospital. Over the years, there were periods in which the committee worked unsystematic way, with sporadic meetings. Nevertheless, it had important consequences on the dynamics of the institution. In addition to duties as foster bioethics debate internally, aiming to collaborate in the training of undergraduate and postgraduate students and health professionals, the committee still had a set of educational activities such as: 1) participation in the annual training course for residents; 2) inclusion of compulsory subject of bioethics in graduate medicine courses in university; 3) creation of the disciplines of bioethics and clinical bioethics – elective graduation in medicine.

Experience with residents (workshop bioethics), recorded in a 2009 article authored by members of the committee at the time <sup>23</sup>, occurred during the second half of 2003 – the result of a partnership with the Committee of Medical Residency (Coreme) hospital - and aimed at stimulating debates on the ethical and bioethical aspects of professional practice in health.

In 2011, already under the mentioned project, contact with some of the members was resumed, especially the Service of Psychiatry and Medical Psychology and coordinator of the committee. It was agreed to resume its regular operation. This year, the meetings were to take place every six months, with the presence of the committee members, residents and graduate students of medicine. In 2012 and 2013, monthly meetings were resumed.

Discussions on the committee revolved around several themes, especially: issues concerning the life of terminally ill ("euthanasia", "futility", "dignified death", "natural death", CFM Resolution 1.805/06, which regulates the so-called "orthotanasia" decision making in the final moments of the life of the patient, lack of palliative care services); confidentiality and the increasing legalization of health. And, yet, the problem of "network" of the health system; lack of integration between the teams, as a consequence it leaves the patient without reference, with discontinuation of treatment; difficulty of treating Jehovah's Witnesses patients and other issues. On the website of the commission no information about the ethical discussions on these aspects of care practice <sup>26</sup>.

In this recovery, a feature that has marked the commission for the adult hospital is the fact of being implemented closer to the bottom-up strategy form, i.e., with the initiative of professionals associated with the school of medicine at the hospital, but without the effective participation of direction. There is also little participation of students from other areas of health beyond medicine. These aspects are presented as challenges for better future analysis.

### **Children's Hospital**

In the children's hospital, the implementation of the bioethics committee occurred in 2011, working with fortnightly meetings at the request of the institution itself for having a high number of cases of moral conflict.

The committee meetings have frequent participation of its members and hospital administration, with intense discussion of the cases. The discussion revolves around very diverse topics such as respect for autonomy of the minor patient; autonomy of parents and the best interests of the child; discharge of patient with chronic life-threatening illness, the family's request, which creates uncertainty in the healthcare team. An emerging theme that became the beginning of the committee's work was the practice of "positive discrimination" facing the patient when contaminated with multidrug-resistant bacteria: is it reasonable to segregate them? What does this mean in terms of treatment? And from the moral point of view?

Three extraordinary meetings were held with professionals to broaden the discussion on this topic – which resulted in a proposed modification of the institutional policy before this situation.

The proposed change occurred through the Committee of Infection Control (CCIH), which pointed out that there is no need for absolute segregation of these contaminated compared to other patients, bringing as arguments a number of technical clarifications as the means of contamination and the ineffectiveness of segregation as a way to prevent new infections. Such technical explanations, however, occurred after an initial process of manifestation of all professionals involved and detection of problems and ways to approach the subject, in which everyone could express opinions, arguments and proposals on the practice of discrimination.

In this case, it is important to highlight that the ethical argument surpassed question the morality of positive discrimination vto propose a model for resolving conflict centered on participation of all the involved ones, to meet the best solution.

#### Psychiatric hospital

At the hospital in question, the deployment process occurred in March 2012, with exposure to the direction of the project and subsequent presentation to the community at the Center for Studies. In May of that year, the first meeting of the bioethics committee at the institution was held. Ordinance 4.125 of the Directorate of 28 May 2012, appointed the members to the committee for 2012-2015.

In this committee, the emerging theme has been the limits of patient autonomy with mental disorders and difficulties to provide care as there is interdependence of legal, social and health aspects of these patients, with the emergence of legal devices such as total prohibitions, compulsory hospitalization by court order. Another sensitive issue is the difficulties of care to drug addicts, who are clients with increased number in recent years, in the hospital. Based on the issues discussed, a lecture to the hospital was planned by the project team, with discussion on the issue of autonomy of beneficiaries with mental disorders.

Absenteeism has been one of the issues of the committee at this institution. Some participants claim heavy workload and lack of time to engage with another activity, which confirms literature data that indicate greater difficulty for the efficient implementation of this structure in psychiatric hospitals. The reasons would be greater competence in teamwork of these professionals, communication and management of conflict situations in daily work, leading them to disregard the need for ethics consultation <sup>27</sup>, this aspect should be the object of further deepening this committee.

#### Maternity

In maternity, the process included the presentation of the project to the direction in late 2012, and to the hospital community, the Centre for Studies in early 2013. After these activities, the unit was internally organized and convened members who could contribute to draw up the ordinance of the commission creation. After these organizational procedures, the schedule was established and the first meeting was discussed the issue of secrecy and confidentiality in maternal and infant care, especially in cases of HIV infection from mother to child.

Other issues discussed were the problem of discharge by default, as well as the difficulties of dealing with babies with extremely low birth weight, a topic which points to the line between abortion and extreme prematurity, and other dilemmas of early life. In educational activities, a lecture (dissemination of research) about the impact on the mother's diagnosis of fetal malformation was performed in order to expand the understanding of the disagreements between family and staff regarding decision making.

#### Discussion

This paper presented the practical experience of implementation and development of bioethics committees in the hospital complex of a Brazilian public university. The initiative is justified, first, by the growing presence of major ethical challenges in clinical practice and, secondly, the need to increase the quality of health care in their collective and individual dimensions by supporting tools, such as committees.

Basically, the strategy of the committees under this project is based in an action plan which seeks to integrate different institutional realities – management and professional body –, so that the committee achieves existence, visibility and consolidate their legitimacy in the health unit. This has proven as true challenge, either by resistance to change, either by poor knowledge of the specificity of these structures. Another strategy is the effective participation of the project team as a member of committees, enabling the exercise of ethics consultation and educational activities.

The four committees which were objects of this work have different settings and issues as well as different levels of understanding of their importance. Each one is under a design phase, with different modes of engagement of their members, and it can be observed that those with higher levels of development are precisely those who can articulate the different levels of the institution, which confirms the literature data presented. Basically, in the committees, one has managed to secure its three main functions. However, these initial moments are more strongly present their educational dimensions and consultation on individual cases.

Although it starts to intensify the perception of the need for bioethics committees, there is limited number of activities in this field. In parallel, some studies <sup>18</sup> show that many health professionals are beginning to accept such discussions but have no basic ethical knowledge and skills to deal with moral issues. Furthermore, there is still little understanding of the fact that ethics is connected to everyday forms of care and technical decisions that are crossed by moral values. Other studies <sup>10</sup> show large differences existing among professionals as to what is considered ethical problem, the ways to solve them and uses of devices and strategies for this purpose – the use of ethics consultation, relying on gut instinct and experience, or even, to older colleagues. These data, by themselves, reveal the actual need for the creation of instances in which these issues can be recognized and discussed.

The studies cited above <sup>10,18</sup>, moreover, indicate that better ethics education can increase sensitivity to these issues in practice and serve as a basis for the development of committees with greater involvement of professional services. Therefore, it is important to increase the teaching of bioethics at all levels, undergraduate, postgraduate etc., including training for committee members and wider dissemination in the social instance, which is one of the organizational aspects that we focus on our experience.

The extension project in question, under a graduate program, has provided the knowledge of different development experiences committees, which helped the creation of such structures in hospitals of a major Brazilian university. This article therefore aims to contribute to the development of committees in our country with the release of paths taken and strategies used to implement also presenting difficulties in order to overcome them in this and other experiments.

It is possible to say that we are still facing a new phenomenon, of which many aspects need to be developed, such as the creation of training programs in ethics consultation; a more systematic review of the effectiveness of their ethical standards in practice; the adequacy of theories and methods to daily exercise in institutions and further research in the field, aiming at identifying the views of health professionals and administrators on the value of committees, their effectiveness, understanding of its features, as well as wider dissemination of existing experience. As we have seen, there is a long way to go before its consolidation as a privileged space in which decisions are made based on a process of reflection and ethical reasoning, with the inclusion of complexity that crosses the clinic. This becomes especially important in times of great technological development that have transformed life into an object of policy-making, revealing the need for choices to be made and reflected way with greater involvement of various actors, and not only the medical doctors.

Finally, we emphasize that these contributions to the debate have the function to start a dialogue with other structures of clinical bioethics in order to facilitate their development and institutionalization in the country. Therefore, we brought some recommendations that can stimulate other initiatives, such as the consideration of the initial stages of deployment 16, so that the problems are not overlooked and lead to failure of the experience.

## **Final considerations**

In line with the presented studies, it is concluded, in their more general aspects, that committees have become a useful tool for referral of cases that require ethical review by enabling their approach in a richer way for broad discussion. The advantages include the search for the role of patients and representatives, as well as offering greater repertoire of actions to professionals and health managers. Finally, commissions contribute to the identification and conduct of ethical dilemmas, both for those involved in the hospital, patients, their families and professionals, and to society in general. In parallel, it is highlighted that an important aspect to be developed in the field of research is the assessment that address, in detail, the performance of committees.

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#### Participation of the authors

Suely Marinho and Alexandre Costa: discussion of the structure, development and final revision of the text – both are part of the implementation team and development of the committees in hospitals; Sergio Rego and Marisa Palácios general coordinators of the extension project also contributed in the discussion of the structure and final revision of the text.

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