

## Bioethics Committee in pediatrics hospital: from proposal to action

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### Abstract

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Hospital bioethics committees (HBC) are characterized as interdisciplinary groups to advise, consult, debate or get involved in decisions and policies related to health ethics. They seek out different looks for conflicts deriving from clinical practice, enabling more comprehensive analysis and more accurate and prudent decision making of ethically problematic situations faced in everyday professional health care. This report, based on case study, aims to encourage reflection and discussion of bioethics linked to health care practice in institutional settings and to present a practical experience in the formation of HBC in a pediatric hospital.

**Key words:** Bioethics. Advisory committees. Interdisciplinary communication.



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The outbreak of bioethics may be considered as the most important social response to the great changes taken place since mid 20th century<sup>1</sup>. It is a typical product of the culture from this period, according to Schramm<sup>2</sup>, and it must face, at least, three main challenges of contemporary culture: the first refers to complexity of phenomena to be analyzed; the second regards the search for a method, indicated by interdisciplinarity and transdisciplinarity terms, supposedly capable to overcome the scission between scientific and humanistic cultures, establishing, in his saying, a "new alliance" among them, while setting bonds between pertinent specialized knowledge and the context in which they are produced in order to emerge new possibilities of knowledge; and, the third concerns knowledge applicability.

It seems clear that the biomedical health care model, characterized among other things by unicausal explanation of disease, by fragmentation, technicality,



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and specialization <sup>3</sup> is unable to satisfactorily respond to these challenges and, in spite of all instrumental sophistication, biomedicine has been incapable to solve many problems, mainly those that are accompanied with psychological and subjective components <sup>4</sup>. For De Rarco <sup>5</sup>, *biomedical model excludes the psychosocial context of meanings, basic for suitable understanding of patient and his disease.*

It is known that technological development carries, implicitly, complex problems that require deep ethical reflection on duties and limitations of professional work, particularly when moral decision-making are necessary <sup>6</sup>. One realizes, when reflecting on pediatrics practice, that current and emerging issues are markedly present, such as cloning, stem-cells, embryos, surrogate mothers, terminality of live, feasibility of preterm birth, palliative care, social vulnerability, autonomy and violence, which have either been discussed or investigated by several scholars and researchers <sup>7-11</sup>.

If, in medical activity technical dimension, competences are currently required for clinical decisions based in evidence, one also notices a growing concern on ethical dimension of care. Experience of several daily situations involving moral values conflicts between health professionals, patients and their families, requires solutions that, often, lead the pediatrician to the necessity of advisory in order to find the best solution.

Historically, physicians have discussed and counted on more experienced colleagues' assistance when they face difficult situations. However, currently, due to expansion of multidisciplinary practice, other professionals are requested to participate in discussions and deliberations <sup>12</sup>. Bioethics committee, considering this imbrication, is a resource that could and must be used in approaching and seeking solutions for moral-ethical problems emerging in clinical

practice situations, involving health professionals, patients and families<sup>13</sup>.

The objective of this brief report is to foster reflection and discussion of bioethics linked to assisting practice in institutional environments and to present a practical experience on constituting a hospital bioethics committee (CHB) in pediatrics hospital.

### **The hospitals bioethics**

Moral, ethical, religious, legal, scientific, and technical aspects are involved in identifying and approaching bioethical problems in a clinical situation<sup>14</sup>, as well as multiple correlations from the social environment from which they emerged, requiring reflection on ideas and concepts that may vary in different cultures and throughout time. Bioethics may be understood, in this sense, as interdisciplinary and interprofessional field of ethics, whose vision expands the discussion of health care to socio-cultural areas in which the situation is inserted<sup>15</sup>.

Differently from the denominated hospital ethics commissions, comprised by members of a single Professional category, CHBs are necessarily multiprofessionals<sup>14</sup> and they may be defined as independent spaces where representatives from several sectors of activities involved with humans' life and health meet, seeking operational solutions for the different ethical problems emerging at institutions<sup>16</sup>.

The first CHB was created in the United States in 1960s, with the objective of setting criteria for attribution of resources available for hemodialysis in chronic kidney patients in hospitals with few equipment and high number of patients. Nevertheless, the first publication in a scientific journal, suggesting the establishment of a hospital bioethics committee as a way to search for dialogue among the several professionals involved in a clinic situation, aiming at sharing responsibility was done in 1972 by pediatrician Karen Teel.

Baby Doe's case in 1982, with enormous public repercussion, involved a legal dispute between the parents of a newborn, with multiple malformations, who did not authorize corrective surgery, and the surgeon – leading the United States government to recommend the establishment of a committee to review pediatrics care<sup>17</sup>.

As one may notice, many of these historical landmarks are related to childhood. In spite of the American Academy of Pediatrics had already recommended in 1984 the establishment of institutional committees (Infants Bioethics Committees), comprised by physicians and non-medical professionals, with educational function, to develop and recommend institutional policies and consultancy on ethical problems or questionings of medical conduct for children<sup>18, 19</sup>, few initiative to structure these committees in pediatrics hospitals are known in Brazil. The pioneering initiative was done by the Porto Alegre Clinics Hospital, when it created the Bioethics Issues Support Program in 1993<sup>13,17</sup>.

We can mention, among the several reasons that justify the creation of a CHB, the complexity of bioethics issues and its multiplicity of options of solution; the growing need to protect institutions and professionals; the recognition of patient's autonomy and religious beliefs of some groups, and the necessity to ethically discuss the allocation of available resources.

CHB must, in practice, comply with at least three functions: educational, normative, and consultative. The educational function is carried out with studies in bioethics within the scope of the committee itself, of the institutional environment and the population at large. The normative function participates in designing of guidelines and institutional policies, and analysis of bioethical features regarding patients' rights and wellbeing. The consultative function takes places through exams and analysis of bioethical cases<sup>14</sup>. In parallel, it is not fit for the CHB to discuss professional malpractice and negligence issues; to solve interpersonal and service problems; to deliberate on legal issues or to sanction or to undertake dispositions with binding character<sup>20</sup>.

Several methods have been developed to discuss and for decision-making in clinical bioethics realm. They all seek for adequate methodologies to solve disputes emerged in caring practice. The key issue is to find the method of analysis that provides the most suitable and correct deliberation. There must be, so this takes place, a process shared with respect and active participation of involved

actors: the physician or the team contribute with its training, knowledge, and skill to diagnosis the sick individual's status, and the indicated or available technical alternatives; the patient or his representative contributes by exposing his legitimate values and needs, through which the risks and benefits of a specific treatment can be analyzed<sup>21</sup>.

### **From proposal to action: the experience of establishing the CHB at Joana de Gusmao Children's Hospital (HIJG)**

In spite of the significant progress achieved with the outbreak of CEP- Conep system that regulates ethics in human research in Brazil, there is not any legislation or guideline on the establishment or operations of bioethics committees in the country<sup>17</sup>. Bioethics emerged organically at the HIJG with the establishment and the beginning of activities of ethics committee in research involving humans (CEP), in early 2005.

In spite of been intensely present in infants and adolescents' daily care, a fact evidenced by the constant incursions of professionals at CEP to discuss clinical bioethics cases, their foundations still were little known and discussed at the institution. Therefore, debates were carried out, initially, with the clinical body and staff from several services, aiming at sensitizing professionals at the institution on the importance of the CHB, its functions, composition, and ways of work.

People from several areas of knowledge were invited for establishing the CHB, either connected or not to the institution, whose professional word and personal trajectory led to ethics and bioethics area.

As Vidal <sup>20</sup> had announced, one sought for assuring different points of view with the presence of physicians, nurses, mental health professionals, social workers, human behavior professionals or from social sciences, such as lawyers and sociologists, both from and off the institution, in addition to participation of management representatives and the institution's volunteers association, knowingly committed with children and families' wellbeing.

An organizing nucleus was established in this group, charged to prepare the diagnosis of the situation, to suggest work methodologies suitable to local reality, to propose by-laws and working rules, to assess physical and human needs, to setup needed logistics, to search for possible sources of funds, as well as to disseminate CHB establishment broadly. CHB was formally established with an administrative act by the institution's board.

The period elapsed between CHB establishment and beginning of normative and consultative activities was depending on the established dynamics. Special care was given in planning continued and permanent bioethics educational activities, both for committee's members and for students, interns, and

the remaining institution's workers. Three workshops were organized at the beginning of educational activities: two of them with participation of invitees with practical experience in bioethics committees from other health institutions; and the other, to discuss methods to approach ethical issues, with a bioethics university professor.

Monthly meeting were subsequently held for case studies described in the literature and presentation of related texts, in addition to discussion of the committee's own working norms. The topics of study were selected, since it is a pediatrics hospital, by prevalence of similar situations knowingly experienced at the institution. The schedules and responsibilities were set since the implementation process, as well as the criteria for continued evaluation of rendered services quality.

The Joana de Gusmão Children's Hospital Bioethics Committee materialized its existence with education activities starting in 2010 and firma-settled itself as basic instance for improving assistance quality provided to assisted infants and community with consultative activities beginning in 2011.

### **Final considerations**

The former decision-making centralized model has been insufficient to respond to new issues derived from accelerated

technological interference, the outbreak of the information society and citizen's increased awareness of their rights to decide about their own health.

CHBs carry the interdisciplinary approach in their essence, seeking different views for the conflicts of value deriving from clinical practice, impartially hearing all involved social actors, enabling a more comprehensive analysis, and seeking to visualize the best outcome for ethically problematic situations.

The report on the experience of setting our Committee may be a way to subsidize the establishment of other CHBs, since they have become increasingly more important for decision-making in view of situations daily faced in pediatrician's Professional work.

One recognizes that there is not a *magical formula* to establish a CHB, and that one of its major challenges is continued training of its members and involved stakeholders, since these committees are spaces for complex and dynamic work, where several areas of knowledge intertwine.

*Work developed during the Medical Sciences graduate program – UFSC and the 2nd course on Clinical and Social Bioethics of Unesco Latin American and Caribbean Bioethics Network (Redbioetica)*

#### **Resumo**

Os comitês hospitalares de bioética (CHB) caracterizam-se como grupos interdisciplinares para aconselhar, consultar, discutir ou envolver-se em decisões e políticas relacionadas a ética na saúde. Buscam diferentes olhares para os conflitos decorrentes da prática clínica, possibilitando a análise mais abrangente e a tomada de decisão mais correta e prudente das situações eticamente problemáticas enfrentadas no cotidiano do exercício profissional de assistência a saúde. Este relato, baseado em estudo de caso, pretende fomentar a reflexão e a discussão da bioética vinculada a prática assistencial nos ambientes institucionais e apresentar uma experiência prática de constituição de CHB em um hospital pediátrico.

**Palavras-chave:** Bioética. Comitês consultivos. Comunicação interdisciplinar.

#### **Resumen**

##### **Comité de bioética en un hospital pediátrico: de la propuesta a la acción**

Los comités hospitalarios de bioética (CHB) se caracterizan como grupos interdisciplinarios para aconsejar, consultar, discutir o involucrarse en decisiones y políticas relacionadas a la ética en la salud. Buscan diferentes puntos de vista para los conflictos derivados de la práctica clínica, posibilitando el análisis más amplio y la toma de decisiones más correcta y prudente de las situaciones éticamente problemáticas enfrentadas en la práctica diaria de los profesionales de asistencia a la salud. Este informe, basado en un estudio de caso, tiene como objetivo promover la reflexión y el debate de la bioética vinculadas a la práctica asistencial en los ambientes institucionales y presentar una experiencia práctica constitución de CHB en un hospital pediátrico.

**Palabras-clave:** Bioética. Comitês consultivos. Comunicación interdisciplinaria.

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### **Authors' participation in the article**

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Jucélia Maria Guedert contributed with the project design and report preparation; and Suely Grosseman contributed with report preparation and review.