

Bioethics hospital committee: successes and difficulties

Kelson Kawamura¹, Maria do Carmo Vicensi², Ricardo José Nodari³, Bruno Rodolfo Schlemper Junior⁴, Elcio Luiz Bonamigo⁵

Abstract

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The objective of this study was to analyze a bioethics hospital committee in its first three years of operation. The study was developed through the analysis of the Minute Book and the application of the Likert questionnaire to its members (scale 1 to 6). 25 of the 36 provided meetings are registered in the Minute Book. The questionnaire results showed that the committee has partially advised the professionals (average 5.08, SD 0.76), reviewed documents (average 5.23, SD 0.83) and promoted training on bioethics to members (average 5.23, SD 0.83). Members were almost unanimous on the importance and continuation of the committee within the institution (average 5.92, SD 0.28). The promotion of training on bioethics to other professionals was considered insufficient (average 4, SD 1.63), as well as its internal promotion (average 4.54, SD 1.20). The main tasks of the committee have been met, and its continuity was supported. In order to solve the encountered problems, a greater promotion of the committee is proposed at the institution, as well as the implementation of bioethics courses to other professionals.

Key words: Bioethics. Ethics committees, clinical. Ethics, institutional. Education, continuing.

Resumo

Este trabalho objetiva analisar o funcionamento de um comitê hospitalar de bioética nos três primeiros anos de funcionamento. O estudo foi desenvolvido mediante análise do livro de atas e aplicação de questionário Likert (escala 1 a 6) aos membros. No livro de atas estão registradas 25 das 36 reuniões previstas. Os resultados do questionário mostraram que o comitê assessorou parcialmente os profissionais (média 5,08+0,76), revisou documentos e promoveu formação em bioética aos seus membros (média 5,23+0,83). Houve quase unanimidade quanto a importância e continuação do comitê na instituição (média 5,92+0,28). A promoção de formação em bioética aos demais profissionais foi considerada insuficiente (média 4+1,63), bem como sua divulgação interna (média 4,54+1,20). As principais funções do comitê foram cumpridas e sua continuidade na instituição foi apoiada. Para solucionar os problemas encontrados propõe-se maior divulgação do comitê na instituição e realização de cursos de bioética aos demais profissionais.

Palavras-chave: Bioética. Comitês de ética clínica. Ética insitucional. Educação continuada.

Resumen

Comité hospitalario de bioética: éxitos y dificultades

El objetivo de este trabajo fue analizar el funcionamiento de un comité hospitalario de bioética en los tres primeros años de operación. El estudio se desarrolló mediante el análisis del libro de acta y la aplicación de un cuestionario Likert (escala 1 a 6) a los miembros. En el libro de acta consta que se celebraron 25 de 36 encuentros previstos. Los resultados del cuestionario mostraron que el comité asesoró parcialmente a profesionales (promedio 5.08+0.76), revisó documentos y promovió la formación en Bioética para los miembros (promedio 5,23+ 0,83). Hubo casi unanimidad respecto a la importancia y la continuidad del comité en la institución (promedio 5,92+0,28). La promoción de la formación en bioética a otros profesionales fue considerada deficiente (promedio 4+1,63), así como su divulgación interna (promedio 4.54+1,20). Las principales funciones del comité se cumplieron y su continuidad en la institución fue apoyada. Para solucionar los problemas encontrados se propone mayor divulgación del Comité en la institución y realización de cursos de bioética a los demás profesionales.

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

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1. Graduation kelson.1989k@hotmail.com 2. Master maria.vicensi@unoesc.edu.br 3. Master ricardo.nodari@unoesc.edu.br 4. Doctor schlemper.junior@gmail.com 5. Doctor elcio.bonamigo@unoesc.edu.br - West Santa Catarina University (Unoesc), Joaçaba Campus, Joaçaba/SC, Brazil.

Address

Elcio Luiz Bonamigo - Rua Francisco Lindner, 310 CEP 89600-000. Joaçaba/SC, Brazil.

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Scientific development enabled human beings to undertake actions that are increasingly more complex and of great responsibility. This aspect assumes particular importance in medical care where science is applied directly to human life. The advance of technological innovations has spurred the outbreak of moral conflicts whose analysis may surpass the realm of professional deontology.

Bioethics committees emerged from this context as organizations that, among other roles, can advise professionals in solving moral conflicts within the scope of hospital ¹. The outbreak of bioethics committees relates to three cases occurring in the United States of America (USA) between 1960 and 1983: the Seattle committees, where there were more patients than machines, while a multi-professional committee was nominate to solve them ²; the Karen Ann Quinlan's case, in which a judge request an opinion from the hospital bioethics committee about her vegetative state, which did not exist and was created hastily ³; and, finally, the case of Baby Doe I, in which the parents did not authorize the surgery in their son who was carrier of the down syndrome and had esophagus atresias that led to his death, causing reaction by the government which recommended the establishment of hospital bioethics committees to deal quickly with cases of this nature ^{2,4,5}.

Committees expanded to Europe and Latin America, although less intensively, after their implementation in the USA. In Brazil, the first Bioethics Committee emerged in 1993, at the Hospital of Clinics in Porto Alegre ^{2,4}. From 2006 the committees were set up in other institutions such as the University of Londrina, Parana, St Luke's Hospital of PUC-RS, and in the Hospital of Clinics at the University of Sao Paulo⁴. Only four committees were identified in the State of Santa Catarina, according to their establishing order in Joinville, Joaçaba, Chapeco e Florianopolis.

Recently, in some countries, such as Spain, Chile and Brazil, there has been a trend in proposing implementation of bioethics committees in the framework of basic health care too ³,

outside hospitals, pointing toward the beginning of their expansion to other health sectors. Nevertheless, the existing hospital bioethics committees may be undergoing through work difficulties as shown in this paper.

Moral conflicts are part of medical care and solutions may surpass the scope of Professional deontological codes. Thus, results the importance of a multi-professional bioethics committee in health institutions, both for solving dilemmas and moral problems, which was the reason for its outbreak in the USA, as well as for the other functions of reviewing document and promoting continued education in bioethics at the institution. The implementation of a bioethics committee presupposes the existence of a group of individuals working toward institutional ethics, helping professionals, fostering patient's caring and respect for his rights and autonomy ¹.

The overall objective of this paper was to analyze the Bioethics Committee's work in the Santa Terezinha University Hospital, from Joaçaba, Santa Catarina, which started working in 2007. OsIts specific objectives were to characterize actions undertaken during the committee's first three years of work; identifying working problems; to contribute with proposals for its optimal work. The project was approved by the institution's Research Ethics committee in July 2011 and receiving the registry FR 441818 in the Sisnep.

Method

This study is characterized as descriptive and retrospective, in which the minutes of all meetings of the Bioethics Committee, since the beginning of its activities in 2007 until the end of its third year of operations in 2009 have been reviewed. A questionnaire was submitted also to its members as supplementary data collection technique. The following features were evaluated in the minutes: 1) periodicity of meetings; 2) discussed topics; 3) members' attendance record.

During the first three years of operations, the committee had two compositions. In order to apply the questionnaire, only those committee's members who participated in at least in one composition related to the study period and had attended one meeting were included. The first three years of operations (2007-2009) were chosen for analysis because they were the most critical period for implementing a committee in which, theoretically, training of its member takes place, and it is the initial performance of its basic roles in promoting bioethics education at the institution, in addition to provide advice to professionals and review bioethical documentation.

The questionnaire had questions, in addition to demographic issues, that were scaled with a pair number of alternatives to identify more precisely the positioning of researched subjects ⁶. Six Likert items, without neuter point, with reply option that varied from fully disagree, partially disagree, slightly disagree to agree slightly, agree partially, and agree totally were made available. In order to compute the average, it was give values from 1 (fully disagree) to 6 (agree totally).

Microsoft Office Excel 2010 software was used to compute statistical data. When interpreting the results, average and standard deviation were considered, since they are the data that translate more clearly the accuracy of meanings found in replies to the Likert items.

Results

Analyzed minutes refer to meeting undertaken between February 2007 and October 2009, adding to 25 meetings. The committee met at the hospital facilities or at the University Medical Unit. Both institutions are under the jurisdiction of the West Santa Catarina University. The Committee was established with the clinical member and professors' Initiative, and it did not count on hospital management participation in its organization. Regarding attendance, there was not quorum only twice.

In other five opportunities, meetings were not scheduled. The number of attending members varied from 3 to 8 (4.8 in average) out of 9 procedurally possible. Medical students attended in all semesters, participating in at least one of the meetings, as complementary task of the Medical ethics course.

During those 25 meetings, 30 topics were approached through lectures, discussion of bioethical issues, training on decision making in ethical dilemmas, and review of informed consent.. Concerning the documentation-reviewing role, the committee analyzed and amended the institution's main informed consent document in two meetings. Regarding advising professionals, two training sessions were carried out, in addition to a retrospective analysis. Education of committee's members took place in 17 out of 25 meetings, and it was the major performed role. Three meetings were dedicated to internal organization (Table 1).

Concerning the application of questionnaire, out of the 15 member participating in the first three years of the bioethics committee operations that met the study population requirement, 13 (86.6%) participated and fully replied to questions. Regarding sampling profile, the male gender prevailed, amounting to 69.2% of members. The age range of interviewed was distributed as follows: 23% aged between 30-39 years old; 30.7% between 40-49 years old, and only 15.3% between 50-59 years, while 30.7% were 60 years old or over.

Regarding professional training, there was greater prevalence of physicians (46.1%), followed by nurses (15.3%), philosophers (15.3%), lawyers (7.6%), social work representative (7.6%), and pedagogue (7,6%).

When questioned about training in ethics, 38.4% replied positively, 40% had readings as source of information, followed by lectures and congresses with 30%; 20% in courses; and 10% had specialization in bioethics.

Table 1. Topics discussed in ethics committee’s meetings during the period of 2007-2009

Date	Topics of meeting	Role
2/1/2007	Palliative sedation	Educational
3/1/2007	Spiritual help	Educational
5/10/2007	Brain death protocol	Educational
6/12/2007	Beginning of life	Educational
8/16/2007	Absence of members in meetings	Organizational
9/20/2007	Orthotanasia	Educational
10/18/2007	Patients in terminal stage	Educational
11/8/2007	Palliative care and decision making	Educational
12/12/2007	How to say the truth	Educational
3/27/2008	Eugenics	Educational
4/17/2008	Request of committee’s bylaws amendment	Organizational
6/19/2008	Organs capture	Educational
7/24/2008	Changes in internal bylaws approved by the hospital	Organizational
8/28/2008	Vital testament	Educational
10/26/2008	Suicide case: decision making	Retrospective advisory
11/27/2008	Euthanasia	Educational
2/26/2009	Vital testament	Educational
3/26/2009	Englaro’s case: decision making simulation	Training in advising
4/23/2009	Establishment of bioethics committees	Organizational
5/29/2009	Bridi’s case: decision making simulation	Training in advising
6/26/2009	Ethics and bioethics in hospital scope	Educational
7/09/2009	Patient’s autonomy	Educational
8/13/2009	Decision on not resuscitating (DRN). Brophy’s case. Persistent vegetative condition. SPP (If halt, halted)	Educational
9/17/2009	Review of informed consent. Patient’s autonomy Order to not resuscitating	Document review and educational
10/29/2009	Review of informed consent	Document review

Source: authors’ survey 2012.

All surveyed members agreed, regarding bioethics Committees’ fulfillment of roles, that it fulfilled its role on advising institution’s professionals in ethical issues.

However, only 30.7% agreed totally, while 46.1% agreed moderately and 23%, slightly. The average was 5.08 and standard deviation 0.76 (Table 2).

Table 2. Main roles performed by the bioethics committee

Topic	Minimum	Maximum	Average	Standard deviation
Advising institution's professionals in bioethics issues Fully disagree 1 2 3 4 5 6 Agree totally	4	6	5,08	0,76
Proposing and reviewing hospital documents on bioethics issues Fully disagree 1 2 3 4 5 6 Agree totally	4	6	5,23	0,83
Promoting training in bioethics for its members Fully disagree 1 2 3 4 5 6 Agree totally	4	6	5,23	0,83
Promoting training in bioethics for health Professionals at the hospital Fully disagree 1 2 3 4 5 6 Agree totally	1	6	4	1,63
The bioethics committee is important for the institution Fully disagree 1 2 3 4 5 6 Agree totally	5	6	5,92	0,28
The continuity of bioethics committee's activities in the institution is recommendable Fully disagree 1 2 3 4 5 6 Agree totally	5	6	5,92	0,28

Source: Authors' survey, 2012.

Concerning the role of proposing and - reviewing bioethics documents, 46.1% of interviewees agreed totally with the statement that the bioethics committee fulfilled its role. Nevertheless, 30.7% agreed moderately and 23% agreed slightly. The average was 5.23 and the standard deviation 0.83.

Concerning fulfilling the role of promoting training in bioethics of its members, 46.1% of interviewees agreed totally, 30.7% agreed moderately and 23% agreed slightly. The average was 5.23 and the standard deviation 0.83.

Regarding the role of promoting training in bioethics for health professionals at the hospital, results varied more: there was total agreement for only 23% of the interviewees, moderate for 7.6%, while 46.1% only agreed slightly.

In parallel, 7.6% slightly disagreed, and 15.3% fully disagreed. The average was 4 and the standard deviation 1.63.

When questioned about the importance of the bioethics committee for the institution in which it is inserted and the need for continuity of its activities, the majority of interviewees (92.3%) totally agreed and only one agreed moderately (7.6%). Both answers presented average of 5.92 and standard deviation of 0.28.

Research subjects stressed, regarding existing problems (Table 3), those related to members themselves, lack of institutional support and from the clinical staff, as well as lack of knowledge on its existence by hospital users.

Table 3. Bioethics committee main problems

Topic	Minimum	Maximum	Average	Standard deviation
Absenteeism (or absence) of its members in meetings Fully disagree 1 2 3 4 5 6 Agree totally	2	6	4,08	1,12
Lack of time of its members to participate in committee's activities Fully disagree 1 2 3 4 5 6 Agree totally	2	6	4,31	1,18
Lack of motivation of its members to participate in committee's activities Fully disagree 1 2 3 4 5 6 Agree totally	1	6	3,69	1,44
Lack of support from the institution Fully disagree 1 2 3 4 5 6 Agree totally	1	6	3,38	1,76
Lack of support from clinical staff Fully disagree 1 2 3 4 5 6 Agree totally	1	6	3,92	1,71
Lack of support for disseminating bioethics committee's usefulness and roles Fully disagree 1 2 3 4 5 6 Agree totally	1	6	4,54	1,20
Lack of training in bioethics of its members Fully disagree 1 2 3 4 5 6 Agree totally	1	6	3,62	1,19
Losing sight of its main role which is to help patients Fully disagree 1 2 3 4 5 6 Agree totally	1	5	3,23	1,30
Absence of procedure for well set work Fully disagree 1 2 3 4 5 6 Agree totally	1	6	2,92	1,61

Source: Authors' survey, 2012.

When requested to express spontaneously their observations on the bioethics committee, interviewees mentioned three problems: 1) clinical staff does not admit interferences; 2) hospital management does not know the role; 3) there should be a basic meeting scheduled for everyone. All proponents unanimously evaluated these three problems with maximum score: 6 points in the Likert scale ("agree totally").

Discussion

It was seen in this study that the bioethics committee approached the most diverse topic related to bioethics in its meetings. End of life, vital testament, palliative sedation, brain death, donation and capture of organs, and how to give bad news to patients were topics of discussions. Realistic simulations were carried out on ethical

investigations in classical cases from literature and training on moral deliberation.

Thus, the bioethics committee, during the survey period, performed normative, consultative, and educational roles, coinciding with the roles describe in literature ^{2,4}. Among the consultative roles are the retrospective and prospective ones. The first refer to cases that had occurred already in the hospital and they serve as basis for prospective deliberations that usually are more urgent ⁷. Retrospective analysis were undertaken once, and literature cases were analyzed twice aiming at training members and to provide basis for future deliberations. There is not any record of prospective analyses.

Regarding gender, the committee composition diverged from literature as it was predominantly comprised by males (69,2%), differently from the CEA-CAT 1 study – one of the major assessment study on bioethics committees carried in Catalonia (Spain), where women were predominant by 57.1% ⁸. Male incidence among medical professionals and theologians are factors that certainly collaborated for this predominance in current study.

Ages of committee's members are distributed in several age ranges, a factor that certainly contributed for the diversity of experiences and standpoints. The predominant age range in this study is 40-65 yrs old, 76.9% of its members. This percentage is close to the result of a study undertaken in Spain, which had a predominance of 74.8% for the 40-65 age range ⁸.

Regarding training of surveyed members, it was found a variety of Professional areas that include philosophers, physicians, nurses, social workers, and one lawyer, ensuring a multi-disciplinary composition. The prevalence of professions in this study was of physicians and nurses with 46.1% and 15.3%, respectively. This datum is similar to the study undertaken in Spain, which had 47.2% of physicians and 22.4% of nurses ⁸, deriving from the fact that these two Professional classes have greater responsibility and professional contact with patients, interpreting the committee as potentially useful for reducing risks ⁹.

Regarding composition, the Ordinance No

29/06 ¹⁰, establishing the bioethics committee of this study, stated the following professions: lawyer, social worker, nurse, philosopher, physician, professor with bioethics training, theologians and one professional representing the community. Nevertheless, not all of them were represented in this study because they did not respond to the questionnaire or because they did not meet the inclusion criteria. This composition is close to Unesco's proposal ¹¹, which recommends the inclusion of bioethicists, philosophers, researchers in sciences of life, health professionals, social and behavioral scientists, scholars in humanities, theologians, health experts, Law, patients' advocates, civil servants, and community representatives.

When questioned about training in bioethics, 61.5% of the research subject responded that they did not have it, while this is a relatively high figure when compared to 11.8% of the Spanish study ⁸. Among those who had training in bioethics, 40% reported reading as their source of information, as it is easily assessed, low cost and requires less hours of dedication, differently of courses or a graduate course in the area. There is not the necessity that all members of the committee to be experts in bioethics, but rather they have moral reflection capability ⁴. This aspect may be stimulated by committee's leadership by providing bibliographic material so members become updated and get sound and based opinions.

Regarding the compliance to its roles, there was unanimous agreement on the merit, but with scaled up valuation. The inquired roles are the following: advising institution's professionals in bioethics issues, proposing and reviewing hospital documents, and promoting training in bioethics for its members. Advisory to professionals had the lowest score. Therefore, this committee has characteristics that many authors interpret as important and basic for the good work of a bioethics committee ^{1,5,12,13}.

The results show that, in parallel, the committee did not fulfill suitably its educational role

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of disseminating bioethics among the institution staff, as the majority of interviewed members understood it this way. Additionally, this question got 4 as average, the lowest average of the first set of questions, the standard deviation had 1.63, evidencing thus a relevant area of deficiency in fulfillment of its roles, since it is one the bioethics committee basic attributions⁵.

In spite of this, all interviewees realized that the bioethics committee is important for the institution to the extent of recommending the continuity of its activities. This seems to show that members have realized the value of the institution's CEP activities in promoting improvements in the clinic-assistance realm. In this sense, in 2000, foreseeing its importance in hospitals, a comment inserted in the International Scenario of the *Brazilian Medical Association's Magazine*¹⁴ predicted a fast growth for bioethics committees in Brazil. However, regarding its theoretical importance, growth occurs paradoxically in a very slow pace. This scenario differs considerably from the evolution in the USA where, from 1% in 1983, reached 60%, in 1989, achieving 83% by end of the 20th Century. Currently, every hospital accredited by the hospital accreditation commission has this committee¹⁵.

Data analysis about the existing problems showed, with 76.9% of participants' opinion, that members' absenteeism in meetings is one of its major causes. Another reason that was pointed out, reinforcing this aspect, is members lack of time to participate in meeting – mentioned by 76.9% of participants.

These problems may influence negatively the committee's work. In addition to this, the non-undertaking of meeting in six opportunities and lack of quorum twice during the period of study adds up (Table 1). In this sense, the absence of members in meeting and the bioethics committee scarce activity, associated to lack of interest for bioethics, set what authors denominate as growth insufficiency syndrome⁸. Thus, initiatives to attract members to meetings are needed in order to prevent that the committee falls into this syndrome. Concerning the difficulties in reconciling interests,

one participant suggested a basic schedule for meetings for all, pointing out the existing difficulties in this regard.

When the topic was lack of support by the institution and shortage in bioethics training for members, there was divergence of opinions: seven (53.8%) of 13 participants agreed with this statement. These responses show the difficulty in identifying the real problems that jeopardize a bioethics committee's performance.

It was evident, in this survey, the lack of streamlining bioethics committee usefulness and roles, since 92.3% of participants agreed with this statement, the highest average in this second set of questions (4,54), associated to a relatively low standard deviation (1,2). This result is confirmed by one of the interviewees' spontaneously recorded observation that "*management does not know the role*", stressing the need to streamline its existence and its roles to hospital staff, and the public at large, as the future of committees depend on the credibility level and social valuation that they achieve during its first years of operations⁹.

However, one may not derive from results that there was deficiency in conducting the committee's work or losing sight of its main role, which is helping patients because both items had the lowest average in this second set of questions. This is a positive aspect, because authors state that, when present, these two factors produce a vague and undetermined feeling about the committee's role, further collaborating for ill functioning^{1,13}. Members should always bear in mind that committees exist particularly to assist and protect patients' interests⁹.

One interviewee expressed, spontaneously, that the clinical staff does not admit interference, showing thus a possible mistrust regarding institution's physicians regarding the hospital committee's roles, which is steering and advisory without a decision making feature on the institution, its collaborators, and staff^{1,13}. In this sense, when the question was lack of support by the clinical staff, 76.9% of respondents agreed to this statement.

Thus, one may interpret that the clinical staff has been reluctant regarding the establishment of the committee in the institution, on the one hand by not admitting interference and on the other by providing insufficient support. Nevertheless, there is not any record of streamlining work with the clinical staff on the bioethics committee's existence and roles by any of its members. Awareness of the clinical staff and of personnel is recommended since the planning period of establishing a committee¹⁶. This problem, however, tends to be solved spontaneously as valuation and prestige of a committed among the institution's health professionals and patients are directly proportional to its functioning period^{8,13}.

Final considerations

This study checked on the main successes and problems in the hospital bioethics committee's first three years of operations, finding that it promoted information lectures and discussions for its members on the most diverse topics of bioethics, fulfilling its educational role. Training was giving through simulation of decision making in two classical cases of the literature. In reference to the document reviewing role, an informed consent was redesigned for the hospital – submitted to patients

at their internship. However, regarding advisory to professionals, only one case was analyzed retrospectively.

One finds that the committee's main roles were fulfilled and it should be maintained in operations at the institution. The main problems that were detected were lack of promoting continued education in bioethics for professionals at the institution, and low dissemination on bioethics committee within the hospital. The following negative points were stressed as well: lack of support by the clinical staff and non-attendance of bioethics committee's members in meetings.

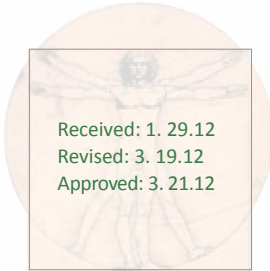
The obtained results enable to design a set of proposals contributing to hospital bioethics committee's work. It is proposed, as solution for the main problems that were found: a) to include in the institution's bylaws the bioethics committee's registry; b) greater dissemination of the bioethics committee in the institution; c) promotion of events for bioethical training of health professionals at the hospital; d) to define more suitable criteria for members selection, setting motivation factors to expand and strengthen their participation. Each committee has its own characteristics and more studies are needed to identify with more accuracy the successes and problems of the first three years of operations of the country's hospital bioethics committees.

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Authors' participation of in the article

- Kelson Kawamura participated in the design, project assembly, data collection and writing. Maria do Carmo Vicensi and Ricardo José Nodari participated in the design and writing. Bruno Schlemper Junior participated in the design, data interpretation, and writing. Elcio Luiz Bonamigo participated in the design, project assembly, data collection, writing, and guidance.



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