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Chapitre 12

CLINICAL BIOETHICS COMMITTEES: A BRAZILIAN EXPERIENCE

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INTRODUCTION

Clinical Bioethics is based on the concept that Medicine is a moral commitment, whose reference relies on its physician-patient relationship. This moral relationship between physician and patient generates co-responsibilities and establishes the context in which shared decisions occur [1]. However, problems of different types may arise in the patient care scenario and require decisions that many times make the physician search for counseling, in order to make the best possible solution for the dilemma in question. The scientific and technological evolution has caused frequent situations with conflicts of moral

values between health professionals and patients, many times involving their families. In order to try to solve problems of this nature, two types of resources are employed. The first one is of personal aspect, in which the individual reflects morally on his/her act and comes to a conclusion regarding the best decision to make. For this purpose, cognitive resources are used, which consist in an awareness of the elements that make up bioethics reflection and the values that are part of his/her personality, created along the lifetime as a result of the experiences acquired from his/her family, school, religion and culture of his/her environment. The decision based solely on "good sense" should be avoided. Many times, "good sense", which is a rational analysis of facts and alternatives, is confused with "common sense", which represents the average thought uncritically accepted. The second resource is to have the support of a Clinical Bioethics Committee, in order to reflect and evaluate questions and moral dilemmas resulting from the practice and procedures performed within the institutions' range, sharing them with other professionals and community representatives [2].

HISTORY

Hospital Bioethics or Ethics Committees were originated in the United States, in the 1960s, when discussions arose on performing hemodialysis in chronic renal patients, since there was a high number of patients and insufficient equipment. The first committee was created from such resource allocation dilemma, composed of laypersons only, and whose purpose was to establish criteria for resource allocation. As it made decisions that involved the survival of patients, this commission was named "Divine Committee" by the lay opinions [3].

The first suggestion for the creation of a Hospital Ethics Committee, published in a scientific periodical, was made by Pediatrician Karen Teel in 1975, in order to enable a dialog between professionals in individual clinical situations,

as a way to share responsibilities [4]. The treatment provided to Karen Ann Quinlan started a judicial dispute between her parents and her assistant physician. The patient lived in a permanent vegetative condition, due to an unexplained cause, and her family wanted the artificial breather to be removed. The physician refused to do that, saying that this resource was necessary to her survival and that the patient did not fulfill the brain death criteria [5]. The sentence of New Jersey Supreme Court in 1976 established that the Ethics Committee of St. Clair Hospital should define the patient's prognosis and ensure that she would never be able to regain a "sapien cognitive state". The judge mistakenly presumed that this hospital already had a Clinical Bioethics Committee, just as most of the other North American hospitals that could evaluate such a situation. As there was no Committee, the Hospital management created one especially to study the case. As a result, it was recommended to remove the breather from the patient [4]. After this fact, the patient still lived for nine years. Also in 1976, Massachusetts General Hospital created a

subcommittee of the Clinical Care Committee, in order to revise 15 cases of

patients with cancer, without apparent possibility of being cured [6]. The results

of such revisions, published by the Committee members, caused significant

repercussion in the medical area [7]. Later, Baby Doe's case in 1982 made a

Northern American State government recommend the creation of committees to revise the pediatric care, which caused an increase in the number of Hospital

Ethics Committees. Baby Doe's case involved a judicial dispute between the parents of a newborn baby with multiple malformations, who did not authorize a

surgery required for the baby's survival, and the surgeon, who insisted on his indication [5]. In July 1987, a new law was in force in the Northern American State of Maryland making the creation of counseling committees mandatory in hospitals, in order to support the decision-making process in cases of health risk diseases. In 1990, this law was extended to include nursing homes [6]. It should be noted that this was the first North American law that made the creation of

Clinical Bioethics Committees mandatory in hospitals. In 1994, the American Hospital Association (AHA) suggested that hospitals should create clinical ethics committees. The North American Presidential Commission was not giving such

recommendations anymore, only requesting hospitals to have ethics education,

consultancy and revision programs in place for difficult cases, which is today's attitude adopted by the North American Hospital Registry Commission [8]. In Brazil, there is no legislation or guideline that regulates the creation or operation of Bioethics Committees. The Hospital de Clinicas de Porto Alegre (HCPA) was the first to implement in 1993 its Support Program to Bioethics Problems

(Programa de Apoio aos Problemas de Bioetica). The Hospital Sao Lucas at Pontificia Universidade Catolica do Rio Grande do Sul created its Bioethics

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THE ROLE OF BIOETHICS COMMITTEES

The purpose of a bioethics consultancy is to improve the standard of patient care, providing the professional in charge of the patient care with an opportunity of better decision making in case of a moral dilemma. A Bioethics Committee can be defined as an interdisciplinary board of people, whose objective is to teach, study, provide consultancy services and suggest

institutional norms on ethical issues [9]. Specialists in Ethics have assumed an

important role in patient care. The authority of the Clinical Ethics specialist has been the subject of great discussions. On the one hand, the Ethics consultant is seen as a specialist in moral theory, a technical consultant similar to a medical specialist, with skills, experience and techniques to solve complex moral dilemmas. On the other hand, the specialist can be seen as a mediator, a

communication facilitator, with the function of clarifying the moral position of the others involved and finding a discussion space where the different opinions

can be addressed, understood and solved [10]. In pluralist societies, the

Bioethics Committees search for solutions to ethical dilemmas based on defensible moral norms. For this reason, they need people with, besides knowledge, characteristics such as moral sensitivity and balance, and who are not controversial and dogmatic. According to Andy Clarck, a specialist in Ethics, this consultant should be a highly competent person to promote a

cooperative moral debate [10]. For this role, the bioethics consultant is expected to have conditions of gathering all information required to understand the case in question and, at the same time, expand the communication between the parties. It is not difficult to see, especially at university hospitals, a patient

with several medical teams taking care of his/her case simultaneously and the professionals never talk to share their decisions. These meetings enable to identify areas of possible scientific and ethical discrepancies. In this sense, the objectives of each person participating in the patient care process should be

clear and defined [10]. It is not necessary to have the group composed of Bioethics specialists only. What is expected from the group members is the

moral reflection capability. The Committee leaders are responsible for

motivating the group members to improve their skills in the Clinical Bioethics field, by providing selected bibliographical material and, preferably, significant to the individual's field of competence, and organize their arguments gradually, less intuitively and more based on facts, doctrines and paradigmatic cases within the Bioethics field.

THE EXPERIENCE OF THE HOSPITAL SAO LUCAS

CLINICAL BIOETHICS COMMITTEE

The Clinical Bioethics Committee of the Hospital Sao Lucas at PUCRS was created in 1997. Its objectives were established in Article 4 of its Internal Bylaw: a) educate both internal and external communities regarding the moral dimension of health professionals practice;

b) support, as a consulting board, all health professionals, patients and representatives who have moral conflicts to be solved or assist and/or provide clarifications in a difficult decision-making case, from the moral viewpoint;

c) propose norms, routines and guidelines to the Institution's central administration related to the protection of patients, health professionals and community members [11].

The Clinical Bioethics Committee of PUCRS is composed of 17 members, there being 1 external member that represents the community and 16 other institutional members, including six physicians, a nurse, a social worker, a psychologist, a bioethics specialist, a lawyer and representatives from: the Hospital Administration, from the Catholic Church, from the Medical Ethics Commission and the University's Research Ethics Committee. All members of the Clinical Bioethics Committee have previous Bioethics education.

The Clinical Bioethics Committee of PUCRS meets monthly and provides on-demand consults requested by involved parties. From 1997 to 2006, 82 consults were addressed, 15 of which requested by the Institution itself in order to obtain advice on specific subjects in the Bioethics area.

The clinical consults were requested by 14 different areas of the Hospital, especially from Internal Medical, Intensive Care Unit, Special Care Unit, Geriatrics, Gynecology and Obstetrics. The main themes addressed by these

consults were: limits of treatment; best treatment choice; blood transfusions in

Jehovah Witness patients, HIV diagnosis disclosure to partners and information protection on aggression threats to third parties [11].

Among the institution's demands for consults from the Clinical Bioethics Committee, the most highlighted was related to patients' privacy preservation, particularly regarding their medical records.

Annually, Pontificia Universidade Catolica do Rio Grande do Sul offers three qualification and improvement activities in Bioethics area: a Basic Course for

beginners, a Winter Course for professionals and an Advanced Course to discuss specific issues. These activities are used as an Ethics and Bioethics continuing education program.

THE EXPERIENCE OF THE HOSPITAL DE CLINICAS DE PORTO ALEGRE CLINICAL BIOETHICS COMMITTEE

The Support Program to Bioethics Problems (Programa de Apoio aos Problemas de Bioetica) of the Hospital de Clinicas de Porto Alegre was created

in 1993 with the purpose of reflecting on the moral dilemmas resulting from the practice and procedures performed in this hospital. Today, the Clinical Bioethics Committee of the HCPA is composed of 18 members: six physicians of different specialties - gastroenterologist, nephrologist, pediatrician, psychiatrist, gynecologist and obstetrician, surgeon and coroner - a nurse, two biologists, a social worker, a hospital administrator, a psychologist, a nutritionist and two lawyers, and also two community representatives and a philosopher - the three latter without relationship with the institution [12].

In November 1993, the first group of professionals associated with the

Program decided that it was necessary a period dedicated to studies and reflections. Only after a ten-month period of study, the group felt able to provide the consultancy services requested by the hospital community.

The Clinical Bioethics Committee of the HCPA usually meets once a month

to discuss the most difficult cases addressed during the consults and recommend

guidelines to the Hospital Administration. Between November 1994 and October 2007, 937 consults were addressed, which can be done on-demand basis or in

systematic activities. Specific on-demand consults can be provided mainly to the hospital wards themselves, or

in other areas of the HCPA Medical Services or in the Bioethics and Science Ethics Research Laboratory. Systematic consults are scheduled in advance with groups of health professionals who have recurring problems which, this way, can be addressed in a proactive manner. Such proactive consults may be provided in areas of the HCPA Services or in other rooms that allow the professionals to interact [12].

In order to provide the on-demand consults, also known as ward bioethics' consults, the Clinical Bioethics Committee of the HCPA has a board composed of five consultants available to provide the services. All consultants have postgraduate studies in Bioethics. Ward consults are preferably provided by two

consultants, in order to avoid a single approach to the problem in question. All consult requests are answered in less than 24 hours.

On-demand consultancy services were mostly requested by assistant physicians, as well as other health professionals, patients, patients' families, members of the Hospital Administration or religious communities. Such consults were requested by 58 different areas of the HCPA, especially by Pediatrics,

Internal Medicine, Psychiatry, Gynecology and Obstetrics, Oncology and Hematology. The main issues addressed by such consults were: the patients' privacy; HIV diagnosis disclosure to partners; late onset genetic diseases; end

of-life decisions; medically assisted reproduction; transsexual surgeries and blood transfusions in Jehovah Witness patients.

Proactive consults were performed in several areas of the HCPA. Clinical Pediatric wards, Pediatric Surgery and Rheumatology services have already received proactive consults. Nowadays, two areas have proactive consults systematically: the Pediatric Intensive Care Unit and the Gender Identity

Disorder Program (PROTIG).

The PROTIG consults are held monthly and their objective is to discuss issues related to transsexual surgical indications, gender disorders diagnosis, patients privacy and name change in patients' civil registrations.

In the Pediatric Intensive Care Unit, a 13 beds unit, the proactive consults are held weekly, always on Wednesday mornings, to discuss bioethical aspects involved in inpatients health care. The weekly discussion allows for the supervision of the evolution of long length of stay patients and for the prevention of either present or possible ethical issues. If required, the team of these areas may request on-demand consult to discuss situations that cannot await a new

meeting. The most frequent themes were: end-of-life decisions, recommendations of procedures, family support and child abuse.

The institution's demands for Clinical Bioethics' consults were related to the Hospital's need to reflect on some themes in order to propose actions to optimize its own operation. The most relevant themes were: patients' privacy; patient records confidentiality; electronic medical records privacy protection; nondiscrimination of patients, particularly in situations of isolation for infection control purposes; rights and obligations of visitors and patients' companions; physical and moral aggression to hospital employees.

The Clinical Bioethics Committee members are encouraged to keep themselves updated on relevant themes, mainly with the bibliographical material

and other educational activities that are available, such as the access to Bioethics

disciplines that have regularly offered since 1996, through the UFRGS Medicine Post-graduation Program.

Since 1997, classes on privacy and confidentiality have been offered in the HCPA to the Hospital's employees. These courses are directed at professionals

working in those various areas where they are in direct or indirect contact with the patients, such as: secretaries of inpatients and outpatients units, professionals related to patients' printed/written or electronic records, to billing,

elevator operators, receptionists, security guards, nutrition delivery area, technician-level and superior level professionals of the Clinical Pathology laboratories, as well as

those involved in those different activities related to human resources management. In 1997, over 1,200 employees were qualified in more than 40 courses. In 1999, Bioethics actions were included in the integration activities to new employees. In 2006 and 2007, new groups were formed to resume discussions on these themes. Forty-five courses were offered to over 1,400 employees. The instructors of these courses are associated with the Clinical

Bioethics Committee or the Research Laboratory of Bioethics and Ethics in Science.

Since 1996 a one-week Introductory Course of Bioethics has been offered annually to the community. Over 2,000 people, such as: graduate and postgraduate students, patient relatives, members of religious groups involved in the health area, health professionals, journalists and community members, have participated in these courses.

For professionals who want to improve their qualification in Clinical Bioethics, the Research Laboratory of Bioethics and Ethics in Science of the

HCPA offers, a Bioethics Committees fellowship, as a continuing education activity, of six-month duration. This course enables professionals from other institutions to implement and develop similar activities in other places.

The Bioethics and Science Ethics Internet site (www.bioetica.ufrgs.br), maintained by the Interinstitutional Research Group in Bioethics, which is located in the Bioethics and Science Ethics Research Laboratory offers texts, slides, audio and video presentations on relevant themes of Clinical Bioethics.

This site has been visited by over 840,000 people from different countries since 1997. Many educational and health care institutions use the site materials as

reference.

COMPARING BRAZILIAN EXPERIENCES TO OTHER COUNTRIES' EXPERIENCES

In bioethical literature, little data on the operation of Clinical Bioethics Committees, both in Brazil and in other countries, are available. However, it is possible to establish some comparisons regarding the way Bioethics' consults are provided, the annual volume of consults and the type of competence related to the Clinical Bioethics Committee, as well as possible legal outcomes from this operation.

Regarding the way the consults have been provided, both the Clinical Bioethics Committee of the Hospital Sao Lucas, since 1997, and the Clinical Bioethics Committee of the Hospital de Clinicas, since 1994, have offered on

demand consultancy services. In England, this type of activity was proposed by the Institutional Clinical Ethics Committee of John Hunter Hospital, Newcastle,

in 1999. They created an Acute Clinical Ethics Service (ACES) to address a need perceived from ethics consultancy services performed in the hospital [13].

Proactive consults, which have been performed in the Hospital de Clinicas since 1997 in the Pediatric Intensive Care Unit, were also described by other authors in 1998, and provided to adult patients in the same clinical situation [14].

Regarding the volume of consults provided, there are some data from different countries. In Norway, a study conducted in 2004 involving 28 hospitals

reported that the Committees held around nine meetings a year and had few cases to evaluate [15]. For instance, the National Hospital of Norway provided 31

bioethics consults in 7 years (1996-2002), which resulted in the average of 4.4 consults/year [16]. In New Zealand, at the Auckland Hospital, few cases have

been submitted to the Bioethics Committee, although the physicians appreciate the activity [17]. In Israel, a study conducted in several hospitals reported that each Committee had an average of two consults/year [18]. In England, the average reported was four consults/year [19]. In the United States, two studies offer some data. The first one studied 113 North American Catholic Hospital Committees, with the average of five consults/year [20]. The second study, involving 600 hospitals, reported an average of three consults/year [21].

The Clinical Bioethics Committee of the Hospital Sao Lucas provides an average of 8.2 consults/year, while the Hospital de Clinicas de Porto Alegre an average of 72 consults/year. One of the factors that may partially justify the averages in

these two Brazilian hospitals is the credibility of the Ethics and Bioethics activities developed in both institutions. In the case of the Clinical Bioethics Committee of the Hospital de Clinicas de Porto Alegre, the higher

number of consults provided can be credited to proactive consults, which is offered as a regular and continuous activity.

The denomination of Hospital Ethics Committees is ambiguous. This denomination could be used to describe a Research Ethics Committee, a Clinical Bioethics Committee and even a Medical Ethics Committee. Due to this ambiguity, is difficult to characterize the legal implications to their members [22]. In Belgium, where this situation has occurred, a proposal was made to clarify the attributions to the Committees: dividing them in two - one for research and one for clinical issues [23].

It already works likes that in Brazil. The deliberative aspect of the Research Ethics Committees, granted by Resolution 196/96 of the Conselho Nacional de

Saude (Brazilian National Health Council), guarantees powers to approve or refuse research projects submitted to them. It causes a legal responsibility to their members that act as representatives to protect the best interests of the society. The Medical Ethics Committee exists in any Brazilian hospital, as a formal recommendation of Federal Council of Medicine. The Medical Ethics Committee

deliberates formally in malpractice cases and other professional issues. On the other hand, Clinical Bioethics Committees do not have any legislation or guidelines giving them either deliberative or consultative attributions.

The Ethics Committee do Soroka Medical Center was created in BeerSheva/Israel in 1998, with executive and deliberative aspect, as it evaluates, and then approves or not, the proposals of treatment interruption and information revelation [24]. In this situation, the members of this Committee assume direct responsibilities for the service provided.

Both Brazilian Clinical Bioethics Committees, at Hospital de Clinicas and at the Hospital Sao Lucas, have only had a counseling function, since they were created, in 1993 and 1997, respectively. This way, the members of these Committees should be exempted from this responsibility, as they do not make decisions, but only help professionals and patients in their decision-making process.

CONCLUSION

Health professionals should conciliate, in addition to scientific and technological knowledge, a solid ethical foundation in their professional practice. We support the idea that a competent professional is the one who gathers scientific, technological and ethical qualifications [25]. The function of the Clinical Bioethics Committees is to help professionals, patients and their

representatives in situations whose decision becomes difficult. This way, by exchanging ideas and opinions, clarifying facts and circumstances, using cases as reference and theoretical approaches of Principles, Human Rights, Virtue Ethics and Alterity, adapted to the situation and by considering the systems of

beliefs and affectivity aspects as inherent to human beings, alternatives may arise, and its consequences, enabling to make the decision for the best possible

solution at the moment [26]. Clinical Bioethics Committees are an important element to humanize activities performed in health institutions, both in their institutional aspects and in the personal level of professionals, patients and their families.

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Chapitre 12

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INTRODUCTION

Clinical Bioethics is based on the concept that Medicine is a moral commitment, whose reference relies on its physician-patient relationship. This moral relationship between physician and patient generates co-responsibilities and establishes the context in which shared decisions occur [1]. However, problems of different types may arise in the patient care scenario and require decisions that many times make the physician search for counseling, in order to make the best possible solution for the dilemma in question. The scientific and technological evolution has caused frequent situations with conflicts of moral values between health professionals and patients, many times involving their families. In order to try to solve problems of this nature, two types of resources are employed. The first one is of personal aspect, in which the individual reflects morally on his/her act and comes to a conclusion regarding the best decision to make. For this purpose, cognitive resources are used, which consist in an awareness of the elements that make up bioethics reflection and the values that are part of his/her personality, created along the lifetime as a result of the experiences acquired from his/her family, school, religion and culture of his/her environment. The decision based solely on "good sense" should be avoided. Many times, "good sense", which is a rational analysis of facts and alternatives, is confused with "common sense", which represents the average thought uncritically accepted. The second resource is to have the support of a Clinical Bioethics Committee, in order to reflect and evaluate questions and moral dilemmas resulting from the practice and procedures performed within the institutions' range, sharing them with other professionals and community representatives [2].

HISTORY

Hospital Bioethics or Ethics Committees were originated in the United States, in the 1960s, when discussions arose on performing hemodialysis in chronic renal patients, since there was a high number of patients and insufficient equipment. The first committee was created from such resource allocation dilemma, composed of laypersons only, and whose purpose was to establish criteria for resource allocation. As it made decisions that involved the survival of patients, this commission was named "Divine Committee" by the lay opinions [3].

The first suggestion for the creation of a Hospital Ethics Committee, published in a scientific periodical, was made by Pediatrician Karen Teel in 1975, in order to enable a dialog between professionals in individual clinical situations,

as a way to share responsibilities [4]. The treatment provided to Karen Ann Quinlan started a judicial dispute between her parents and her assistant physician. The patient lived in a permanent vegetative condition, due to an unexplained cause, and her family wanted the artificial breather to be removed. The physician refused to do that, saying that this resource was necessary to her survival and that the patient did not fulfill the brain death criteria [5]. The sentence of New Jersey Supreme Court in 1976 established that the Ethics Committee of St. Clair Hospital should define the patient's prognosis and ensure that she would never be able to regain a "sapient cognitive state". The judge mistakenly presumed that this hospital already had a Clinical Bioethics Committee, just as most of the other North American hospitals that could evaluate such a situation. As there was no Committee, the Hospital management created one especially to study the case. As a result, it was recommended to remove the breather from the patient [4]. After this fact, the patient still lived for nine years. Also in 1976, Massachusetts General Hospital created a subcommittee of the Clinical Care Committee, in order to revise 15 cases of patients with cancer, without apparent possibility of being cured [6]. The results of such revisions, published by the Committee members, caused significant repercussion in the medical area [7]. Later, Baby Doe's case in 1982 made a Northern American State government recommend the creation of committees to revise the pediatric care, which caused an increase in the number of Hospital Ethics Committees. Baby Doe's case involved a judicial dispute between the parents of a newborn baby with multiple malformations, who did not authorize a surgery required for the baby's survival, and the surgeon, who insisted on his indication [5]. In July 1987, a new law was in force in the Northern American State of Maryland making the creation of counseling committees mandatory in hospitals, in order to support the decision-making process in cases of health risk diseases. In 1990, this law was extended to include nursing homes [6]. It should be noted that this was the first North American law that made the creation of Clinical Bioethics Committees mandatory in hospitals. In 1994, the American Hospital Association (AHA) suggested that hospitals should create clinical ethics committees. The North American Presidential Commission was not giving such recommendations anymore, only requesting hospitals to have ethics education, consultancy and revision programs in place for difficult cases, which is today's attitude adopted by the North American Hospital Registry Commission [8]. In Brazil, there is no legislation or guideline that regulates the creation or operation of Bioethics Committees. The Hospital de Clínicas de Porto Alegre (HCPA) was the first to implement in 1993 its Support Program to Bioethics Problems (*Programa de Apoio aos Problemas de Bioética*). The Hospital Sao Lucas at Pontifícia Universidade Católica do Rio Grande do Sul created its Bioethics Committee in 1995.

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THE ROLE OF BIOETHICS COMMITTEES

The purpose of a bioethics consultancy is to improve the standard of patient care, providing the professional in charge of the patient care with an opportunity of better decision making in case of a moral dilemma. A Bioethics Committee can be defined as an interdisciplinary board of people, whose objective is to teach, study, provide consultancy services and suggest institutional norms on ethical issues [9]. Specialists in Ethics have assumed an important role in patient care. The authority of the Clinical Ethics specialist has been the subject of great discussions. On the one hand, the Ethics consultant is seen as a specialist in moral theory, a technical consultant similar to a medical specialist, with skills, experience and techniques to solve complex moral dilemmas. On the other hand, the specialist can be seen as a mediator, a communication facilitator, with the function of clarifying the moral position of the others involved and finding a discussion space where the different opinions can be addressed, understood and solved [10]. In pluralist societies, the Bioethics Committees search for solutions to ethical dilemmas based on defensible moral norms. For this reason, they need people with, besides knowledge, characteristics such as moral sensitivity and balance, and who are not controversial and dogmatic. According to Andy Clarck, a specialist in Ethics, this consultant should be a highly competent person to promote a cooperative moral debate [10]. For this role, the bioethics consultant is expected to have conditions of gathering all information required to understand the case in question and, at the same time, expand the communication between the parties. It is not difficult to see, especially at university hospitals, a patient with several medical teams taking care of his/her case simultaneously and the professionals never talk to share their decisions. These meetings enable to identify areas of possible scientific and ethical discrepancies. In this sense, the objectives of each person participating in the patient care process should be clear and defined [10]. It is not necessary to have the group composed of Bioethics specialists only. What is expected from the group members is the moral reflection capability. The Committee leaders are responsible for motivating the group members to improve their skills in the Clinical Bioethics field, by providing selected bibliographical material and, preferably, significant to the individual's field of competence, and organize their arguments gradually, less intuitively and more based on facts, doctrines and paradigmatic cases within the Bioethics field.

THE EXPERIENCE OF THE HOSPITAL SÃO LUCAS CLINICAL BIOETHICS COMMITTEE

The Clinical Bioethics Committee of the Hospital Sao Lucas at PUCRS was created in 1997. Its objectives were established in Article 4 of its Internal Bylaw:

- a) educate both internal and external communities regarding the moral dimension of health professionals practice;
- b) support, as a consulting board, all health professionals, patients and representatives who have moral conflicts to be solved or assist and/or provide clarifications in a difficult decision-making case, from the moral viewpoint;
- c) propose norms, routines and guidelines to the Institution's central administration related to the protection of patients, health professionals and community members [11].

The Clinical Bioethics Committee of PUCRS is composed of 17 members, there being 1 external member that represents the community and 16 other institutional members, including six physicians, a nurse, a social worker, a psychologist, a bioethics specialist, a lawyer and representatives from: the Hospital Administration, from the Catholic Church, from the Medical Ethics Commission and the University's Research Ethics Committee. All members of the Clinical Bioethics Committee have previous Bioethics education.

The Clinical Bioethics Committee of PUCRS meets monthly and provides on-demand consults requested by involved parties. From 1997 to 2006, 82 consults were addressed, 15 of which requested by the Institution itself in order to obtain advice on specific subjects in the Bioethics area.

The clinical consults were requested by 14 different areas of the Hospital, especially from Internal Medical, Intensive Care Unit, Special Care Unit, Geriatrics, Gynecology and Obstetrics. The main themes addressed by these consults were: limits of treatment; best treatment choice; blood transfusions in Jehovah Witness patients, HIV diagnosis disclosure to partners and information protection on aggression threats to third parties [11].

Among the institution's demands for consults from the Clinical Bioethics Committee, the most highlighted was related to patients' privacy preservation, particularly regarding their medical records.

Annually, Pontificia Universidade Catolica do Rio Grande do Sul offers three qualification and improvement activities in Bioethics area: a Basic Course for

beginners, a Winter Course for professionals and an Advanced Course to discuss specific issues. These activities are used as an Ethics and Bioethics continuing education program.

THE EXPERIENCE OF THE HOSPITAL DE CLINICAS DE PORTO ALEGRE CLINICAL BIOETHICS COMMITTEE

The Support Program to Bioethics Problems (*Programa de Apoio aos Problemas de Bioetica*) of the Hospital de Clinicas de Porto Alegre was created in 1993 with the purpose of reflecting on the moral dilemmas resulting from the practice and procedures performed in this hospital. Today, the Clinical Bioethics Committee of the HCPA is composed of 18 members: six physicians of different specialties – gastroenterologist, nephrologist, pediatrician, psychiatrist, gynecologist and obstetrician, surgeon and coroner – a nurse, two biologists, a social worker, a hospital administrator, a psychologist, a nutritionist and two lawyers, and also two community representatives and a philosopher – the three latter without relationship with the institution [12].

In November 1993, the first group of professionals associated with the Program decided that it was necessary a period dedicated to studies and reflections. Only after a ten-month period of study, the group felt able to provide the consultancy services requested by the hospital community.

The Clinical Bioethics Committee of the HCPA usually meets once a month to discuss the most difficult cases addressed during the consults and recommend guidelines to the Hospital Administration. Between November 1994 and October 2007, 937 consults were addressed, which can be done on-demand basis or in systematic activities. Specific on-demand consults can be provided mainly to the hospital wards themselves, or in other areas of the HCPA Medical Services or in the Bioethics and Science Ethics Research Laboratory. Systematic consults are scheduled in advance with groups of health professionals who have recurring problems which, this way, can be addressed in a proactive manner. Such proactive consults may be provided in areas of the HCPA Services or in other rooms that allow the professionals to interact [12].

In order to provide the on-demand consults, also known as ward bioethics' consults, the Clinical Bioethics Committee of the HCPA has a board composed of five consultants available to provide the services. All consultants have postgraduate studies in Bioethics. Ward consults are preferably provided by two

consultants, in order to avoid a single approach to the problem in question. All consult requests are answered in less than 24 hours.

On-demand consultancy services were mostly requested by assistant physicians, as well as other health professionals, patients, patients' families, members of the Hospital Administration or religious communities. Such consults were requested by 58 different areas of the HCPA, especially by Pediatrics, Internal Medicine, Psychiatry, Gynecology and Obstetrics, Oncology and Hematology. The main issues addressed by such consults were: the patients' privacy; HIV diagnosis disclosure to partners; late onset genetic diseases; end-of-life decisions; medically assisted reproduction; transsexual surgeries and blood transfusions in Jehovah Witness patients.

Proactive consults were performed in several areas of the HCPA. Clinical Pediatric wards, Pediatric Surgery and Rheumatology services have already received proactive consults. Nowadays, two areas have proactive consults systematically: the Pediatric Intensive Care Unit and the Gender Identity Disorder Program (PROTIG).

The PROTIG consults are held monthly and their objective is to discuss issues related to transsexual surgical indications, gender disorders diagnosis, patients privacy and name change in patients' civil registrations.

In the Pediatric Intensive Care Unit, a 13 beds unit, the proactive consults are held weekly, always on Wednesday mornings, to discuss bioethical aspects involved in inpatients health care. The weekly discussion allows for the supervision of the evolution of long length of stay patients and for the prevention of either present or possible ethical issues. If required, the team of these areas may request on-demand consult to discuss situations that cannot await a new meeting. The most frequent themes were: end-of-life decisions, recommendations of procedures, family support and child abuse.

The institution's demands for Clinical Bioethics' consults were related to the Hospital's need to reflect on some themes in order to propose actions to optimize its own operation. The most relevant themes were: patients' privacy; patient records confidentiality; electronic medical records privacy protection; non-discrimination of patients, particularly in situations of isolation for infection control purposes; rights and obligations of visitors and patients' companions; physical and moral aggression to hospital employees.

The Clinical Bioethics Committee members are encouraged to keep themselves updated on relevant themes, mainly with the bibliographical material and other educational activities that are available, such as the access to Bioethics

disciplines that have regularly offered since 1996, through the UFRGS Medicine Post-graduation Program.

Since 1997, classes on privacy and confidentiality have been offered in the HCPA to the Hospital's employees. These courses are directed at professionals working in those various areas where they are in direct or indirect contact with the patients, such as: secretaries of inpatients and outpatients units, professionals related to patients' printed/written or electronic records, to billing, elevator operators, receptionists, security guards, nutrition delivery area, technician-level and superior level professionals of the Clinical Pathology laboratories, as well as those involved in those different activities related to human resources management. In 1997, over 1,200 employees were qualified in more than 40 courses. In 1999, Bioethics actions were included in the integration activities to new employees. In 2006 and 2007, new groups were formed to resume discussions on these themes. Forty-five courses were offered to over 1,400 employees. The instructors of these courses are associated with the Clinical Bioethics Committee or the Research Laboratory of Bioethics and Ethics in Science.

Since 1996 a one-week Introductory Course of Bioethics has been offered annually to the community. Over 2,000 people, such as: graduate and postgraduate students, patient relatives, members of religious groups involved in the health area, health professionals, journalists and community members, have participated in these courses.

For professionals who want to improve their qualification in Clinical Bioethics, the Research Laboratory of Bioethics and Ethics in Science of the HCPA offers, a Bioethics Committees fellowship, as a continuing education activity, of six-month duration. This course enables professionals from other institutions to implement and develop similar activities in other places.

The Bioethics and Science Ethics Internet site (www.bioetica.ufrgs.br), maintained by the Interinstitutional Research Group in Bioethics, which is located in the Bioethics and Science Ethics Research Laboratory offers texts, slides, audio and video presentations on relevant themes of Clinical Bioethics. This site has been visited by over 840,000 people from different countries since 1997. Many educational and health care institutions use the site materials as reference.

COMPARING BRAZILIAN EXPERIENCES TO OTHER COUNTRIES' EXPERIENCES

In bioethical literature, little data on the operation of Clinical Bioethics Committees, both in Brazil and in other countries, are available. However, it is possible to establish some comparisons regarding the way Bioethics' consults are provided, the annual volume of consults and the type of competence related to the Clinical Bioethics Committee, as well as possible legal outcomes from this operation.

Regarding the way the consults have been provided, both the Clinical Bioethics Committee of the Hospital Sao Lucas, since 1997, and the Clinical Bioethics Committee of the Hospital de Clinicas, since 1994, have offered on-demand consultancy services. In England, this type of activity was proposed by the Institutional Clinical Ethics Committee of John Hunter Hospital, Newcastle, in 1999. They created an Acute Clinical Ethics Service (ACES) to address a need perceived from ethics consultancy services performed in the hospital [13].

Proactive consults, which have been performed in the Hospital de Clinicas since 1997 in the Pediatric Intensive Care Unit, were also described by other authors in 1998, and provided to adult patients in the same clinical situation [14].

Regarding the volume of consults provided, there are some data from different countries. In Norway, a study conducted in 2004 involving 28 hospitals reported that the Committees held around nine meetings a year and had few cases to evaluate [15]. For instance, the National Hospital of Norway provided 31 bioethics consults in 7 years (1996-2002), which resulted in the average of 4.4 consults/year [16]. In New Zealand, at the Auckland Hospital, few cases have been submitted to the Bioethics Committee, although the physicians appreciate the activity [17]. In Israel, a study conducted in several hospitals reported that each Committee had an average of two consults/year [18]. In England, the average reported was four consults/year [19]. In the United States, two studies offer some data. The first one studied 113 North American Catholic Hospital Committees, with the average of five consults/year [20]. The second study, involving 600 hospitals, reported an average of three consults/year [21].

The Clinical Bioethics Committee of the Hospital Sao Lucas provides an average of 8.2 consults/year, while the Hospital de Clinicas de Porto Alegre an average of 72 consults/year. One of the factors that may partially justify the averages in these two Brazilian hospitals is the credibility of the Ethics and Bioethics activities developed in both institutions. In the case of the Clinical Bioethics Committee of the Hospital de Clinicas de Porto Alegre, the higher

number of consults provided can be credited to proactive consults, which is offered as a regular and continuous activity.

The denomination of Hospital Ethics Committees is ambiguous. This denomination could be used to describe a Research Ethics Committee, a Clinical Bioethics Committee and even a Medical Ethics Committee. Due to this ambiguity, is difficult to characterize the legal implications to their members [22]. In Belgium, where this situation has occurred, a proposal was made to clarify the attributions to the Committees: dividing them in two – one for research and one for clinical issues [23].

It already works like that in Brazil. The deliberative aspect of the Research Ethics Committees, granted by Resolution 196/96 of the Conselho Nacional de Saude (*Brazilian National Health Council*), guarantees powers to approve or refuse research projects submitted to them. It causes a legal responsibility to their members that act as representatives to protect the best interests of the society. The Medical Ethics Committee exists in any Brazilian hospital, as a formal recommendation of Federal Council of Medicine. The Medical Ethics Committee deliberates formally in malpractice cases and other professional issues. On the other hand, Clinical Bioethics Committees do not have any legislation or guidelines giving them either deliberative or consultative attributions.

The Ethics Committee do Soroka Medical Center was created in Beer-Sheva/Israel in 1998, with executive and deliberative aspect, as it evaluates, and then approves or not, the proposals of treatment interruption and information revelation [24]. In this situation, the members of this Committee assume direct responsibilities for the service provided.

Both Brazilian Clinical Bioethics Committees, at Hospital de Clinicas and at the Hospital Sao Lucas, have only had a counseling function, since they were created, in 1993 and 1997, respectively. This way, the members of these Committees should be exempted from this responsibility, as they do not make decisions, but only help professionals and patients in their decision-making process.

CONCLUSION

Health professionals should conciliate, in addition to scientific and technological knowledge, a solid ethical foundation in their professional practice. We support the idea that a competent professional is the one who gathers scientific, technological and ethical qualifications [25]. The function of the Clinical Bioethics Committees is to help professionals, patients and their

representatives in situations whose decision becomes difficult. This way, by exchanging ideas and opinions, clarifying facts and circumstances, using cases as reference and theoretical approaches of Principles, Human Rights, Virtue Ethics and Alterity, adapted to the situation and by considering the systems of beliefs and affectivity aspects as inherent to human beings, alternatives may arise, and its consequences, enabling to make the decision for the best possible solution at the moment [26]. Clinical Bioethics Committees are an important element to humanize activities performed in health institutions, both in their institutional aspects and in the personal level of professionals, patients and their families.

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