Profile of clinical bioethics consultancies involving families which hindered the resolution of problems

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Abstract

This study evaluated 116 records of clinical bioethics consultation in which the patients' family made difficult the resolution of the problem or ethical conflict. The following aspects were evaluated: Applicants, Medical Specialties, Electronic Health Records, Patients and Family Relationships. Physicians requested 71% of the Bioethics consultation. The Internal Medicine, Pediatrics and Psychiatry Services demanded the majority number of consultations (56%). The patients who had their consultations registered in electronic medical records were 79%. As for response, 71% of consultations were seen on the same day or the day after requested. The percentages of male and female patients were, respectively, 48% and 52% with a mean age of 28 years, 54% of the patients were from Porto Alegre. The naturally imposed family relationships (71%) were the more prevalent. It is very import that other studies be performed in order to generate adequate comprehension about ethical problems and their possible solutions.

Key words: Bioethics. Ethics consultation. Family. Family relations.

Resumo

Perfil das consultorias de bioética clínica envolvendo famílias que dificultaram a resolução de problemas

Este estudo avaliou 116 consultorias de bioética clínica nas quais as famílias dos pacientes dificultaram a resolução do problema ou do conflito ético. Foram observados os seguintes aspectos: solicitantes; especialidades; registros nos prontuários eletrônicos; pacientes e relações familiares. A maior parte das consultorias (71%) foi gerada pelas solicitações dos médicos. Os serviços de Medicina Interna, Pediatria e Psiquiatria demandaram 56% das consultorias. Foram encontrados registros de pedidos de consultoria nos prontuários de 79% dos pacientes, dos quais 71% foram respondidos no mesmo dia ou no seguinte. O número de consultorias por sexo do paciente foi semelhante e a idade média, de 28 anos. Em relação à procedência, 54% eram de Porto Alegre. As relações familiares naturalmente impostas (71%) foram mais identificadas. É importante que outros estudos sejam realizados com vistas a permitir um adequado entendimento dos problemas éticos e de suas possíveis resoluções.

Palavras-chave: Bioética. Consultoria ética. Família. Relações familiares.

Resumen

Perfil de las consultoría de bioética clínica con familias que dificultaron la resolución de problemas

Este estudio evaluó 116 consultorías de bioética clínica en las cuales las familias de los pacientes dificultaron la resolución del problema o conflicto ético. Se evaluaron los siguientes aspectos: solicitantes, especialidades, asientos de registros médicos electrónicos, pacientes y relaciones familiares. La mayoría de las consultorías (71%) fue generada por las peticiones de los médicos. Los Servicios de Medicina Interna, Pediatría y Psiquiatría demandaron 56% de las consultorías. Se han encontrado asientos de consultoría en los registros médicos en 79% de los pacientes, de los cuales 71% fueron respondidas el mismo día o el siguiente. El número de consultorías por sexo del paciente fue similar y promedio de edad fue de 28 años. En cuanto al origen, 54% eran de Porto Alegre. Las relaciones familiares, naturalmente, impuestas (71%) fueron más marcantes. Es importante que otros estudios se lleven a cabo para permitir una adecuada comprensión de los problemas éticos y sus posibles soluciones.

Palabras-clave: Bioética. Consultoría ética. Família. Relaciones familiares.

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Research article

During the health care service, problems or ethical conflicts which require a further discussion may arise. The complex Bioethics can help in this discussion, because it is a comprehensive proposal of approaching to solve problems which involve life and living. Therefore, it seeks the maximum of information with a view to better understanding of the problem, evaluates the facts and circumstances involved to identify the alternatives, considering their respective consequences. In this discussion, there are included theoretical references and related cases. Besides these elements, two other components should be considered: the system of values and beliefs, which involves the traditions and interests, and affection, which are regarded to the wishes and links[1] .

The Clinical Bioethics deals with problems or conflicts which may arise during the service in health care [1,2]. There are several methodological approaches to the analysis of problems or conflicts involved in decision making, whether in medical practice or practice of other professionals in the health field.

With the aim to develop activities to support professionals, patients and family members who have ethical problems emerged from practices and procedures in the hospital, in November 1993, it was created, at the Hospital de Clínicas de Porto Alegre (HCPA), the Program for Attention to the Clinical Bioethics Problems[3]. During one year, the working group, formed by an interdisciplinary team, studied and developed skills to provide consultation in clinical bioethics, activity which was started exactly a year later, in November 1994[3]. Subsequently, the working group was constituted as the Committee on Clinical Bioethics of HCPA. This collegiate consists of members from different areas of expertise and assistance in the hospital, besides community representatives, and holds monthly systematic meetings in order to discuss the cases from the consultation which require further reflection and proposals for institutional actions[4].

In 2009, the Service of Bioethics was created in HCPA, officially recognized as a specialty of care[5]. With this change, the consultation of clinical bioethics has started to be carried out by the Bioethics Services and registered in the electronic medical records of each patient. Currently, this service complies with two types of consultation: health care and proactive demands.

The clinical bioethics consultancy seeks to help in the discussion about ethical issues which difficult the decision making on the part of the care team, patients and their family members. The clinical bioethics consultant is someone trained to be able to assist in this process, questioning and expanding the alternatives which can serve as a solution[6]. The responses of the consultants are always under discussions and suggested behaviors, and help in decision making, but they are not decisions themselves.

The consultancy for health care demand is requested by professional staff, by the patient or their family members when a situation which deserves it occurs, at the discretion of such people, an aid in their discussion. The consultancy for health care demands can be requested through the computerized hospital management (AGH), by phone or in person to the Bioethics Service. In order to document properly the situations approached which may have ramifications, it is preferable that all consultants are requested to the AGH system. Thus, the observations of Bioethics Service are safeguarded in the patient record, allowing registering, monitoring and sharing among the teams which assist him. In the years 2010 and 2011 307 consultancy of clinical bioethics by health care demand were recorded.

The proactive consultancy is carried out in regular *rounds* of clinical care teams. The Bioethics consultants attend these *rounds* assisting in the identification and referral of ethical questions presented or envisioned during the clinical discussion of each patient's team. If there is need for a formal record of bioethical considerations, the care team can open a request for consultancy on demand, allowing the access and recording of data in patient records.

All the bioethics consultancy, whether on demand or proactive, are reviewed in weekly clinical meeting of the Bioethics Service. The Clinical Bioethics Committee, which meets monthly, comprehensively discusses the situations arising from these consultations and deserving of a further deepening or the elaboration of a formal opinion of this collective body. Example of such a situation is the assessment of the willingness of donors to inter-living transplants. In all these activities, the consultants and the Committee on Clinical Bioethics use a wide range of theoretical references, involving the ethics of virtue, principialism, human rights and otherness. This plural[2], interdisciplinary, shared and complex perspective [1], is the responsible for a real inclusion of clinical bioethics in health care activities.

Different situations can cause or be involved in a clinical bioethics consultancy, including family conflicts [7]. In a study carried out by another institution, families were the most important reasons to 18.3% of the consultancies [8]. In another research, 10 categories were organized involving the main reasons which led to requests for consultancy. The catego-

ry emphasized, with about a third of the requests, refers to the demand of doctors for help to solve a problem. Some of these requests has involved family relationships of patients. The second category described (10%) specifically refers to the difficulty in interaction with a difficult patient or a family member. Two reports from medical doctors illustrate this difficulty: "*The substitute was unreasonable and not consistent with what the patient said*" and "*there was indecision and quarrels in the family*." [9] Family relationships were reported in most (57%) of the 307 consultancies held in HCPA in 2010-2011. In 116 (38%) consultancies, the families hindered the process of decision making [10].

The patients' families are an important system of care and need to be taken into consideration in care assistance [11]. These family relationships can naturally be imposed, such as parents and children, siblings, or free choice [12]. Whenever possible, it is important to talk with patients and their families. Thus, details of the family context as well as on the patient's values will be known, favoring the willingness to find alternatives which respect them. The contact with family allows us to offer support in their decision making and their sufferings [13].

The present study evaluated the 116 clinical bioethics consultancies in which family relationships of patients prompted an ethical problem or conflict or they hampered its resolution, seeking to establish a profile of the applicants, the specialties involved, the medical records, patients and family relationships.

Method

We evaluated the 116 consultancies of clinical bioethics demand for healthcare, in which patients' family relationships hindered the resolution of the problem or ethical conflict. These consultatncies were conducted by the Office of Bioethics from HCPA between the years 2010 and 2011, when the formal record of these activities was started.

The data were collected from the records of the consultancies provided by the Bioethics Service and electronic medical records of patients related to these activities, arranged in computerized hospital management. For this study, the proactive consultancies carried out in *clinical rounds* of different care teams were not considered, meetings of the Bioethics Service and the Committee of Clinical Bioethics, nor the healthcare consultancies on demand in which families were not involved or did not create difficulty to solve the problem or ethical conflict.

The consultancies were evaluated under the following aspects: characterization of appliers; specialties involved; electronic medical records, including the time and number of response for each consultancy; demographic data and type of patient discharge and characteristics of family relationships, if they were naturally imposed and/or by free choice. The authors signed a term sheet to use the data and the project was previously approved by the institutional Research Ethics Committee (CEP).

Results and Discussion

The consultancies of clinical bioethics from HCPA were requested to the Bioethics Service by different people related to the institution: medical doctors, nurses, administrators, medical students (residency) and family. From the 116 reports evaluated, 99 (85.35%) contained the identification of who was the applier.

Most part of the consultancies – 82 (70.69%) – was requested by physicians. This proportion is identical to a study conducted in the United States, in which 68% of consultancies were also requested by physicians [7] – the nurses demanded 13 consultancies (11.21%). In the American study, the nurses were responsible for 22% of requests [14]. Administrators made the request of two consultancies (1.72%). The academics, working in care teams, and the family made only one request each (0.86%).

The specialties were identified in 114 (98.27%) of the 116 reports of clinical bioethics consultancy evaluated. The service of health care related to request of consultancy was considered as a specialty. Four services – Internal Medicine, Pediatrics (including ICU), Pediatric Oncology and Psychiatry – were responsible for 65 requests of consultancies (56.03%). The remaining 49 requests were made by other 18 services.

As in the present study, in two other studies the Internal Medicine, Pediatrics and Psychiatry were also reported as being the specialties which most demanded consultancies [8.15]. In these same studies, the intensive care units are cited as important sources of consultancies requests. In pediatric and adult intensive care units from HCPA are carried out proactive consultancies, i.e. bioethics consultants participate in weekly clinical *rounds*, in which are discussed the current or potential ethical aspects of all hospitalized patients. These discussions

resolve, in a preventive manner, many of the situations which tend to become problematic. Thus, the number of requests for consultancies on demand is reduced in those units.

The 116 reports of consultancy evaluated were associated to 84 patients with 1.38 consultancies/patient. From the total of 116, medical records of patients were identified in 90 reports, while in 26 reports it was not possible to verify the identification data of patients who could allow the access to their medical records. The 90 consultancy reports cited, whose identification of the record was possible, were from 66 (78.57%) of 84 patients. The other 26 reports cited, with no data which could relate to the identification of medical records, were associated to 18 (21.43%) of the 84 patients.

In two requests for consultancy, it was not possible to obtain the report through the records, because in a situation which the patient was discharged before the response to the request of the team and in another one two professional requested consultancies on a same patient, nearly simultaneously. In this case, there was record from only one of them. The number of answers per consultancy ranged from one to four.

The consultancies of clinical bioethics had average time of response between one and three days, considering precisely the period between the request and the response of 1.37+2.31 days. Most consultancies were answered in a brief period, with 35 in the same day of request (50.72%) and another 14 in the next day (20.29%). The longest period recorded was 11 days. This data is close to the story of the institution of Chile, where the request for consultancy is also fulfilled between 24 and 28 hours [13]. In a research with Norwegian physicians, 23% said they had received the response in a few days, while the remaining 77% said they expected more than two weeks [14]. As in HCPA, in other institutions, such as from Chile, the consultancies which require more discussion are taken again at meetings of the Committee of Clinical Bioethics [13].

Regarding the record, it is relevant to note that this study evaluated the clinical bioethics consultancies through the records of the Bioethics Service. Because not all consultancies are required to the Service of Bioethics through the electronic medical records of patients, some data from certain consultancies were not collected due to lack of a proper record. This demonstrates the importance of valuing the request for consultancy through the electronic medical records of patients.

When these consultancies are requested through electronic records, the Bioethics Service can document, in writing, their answers. In a study involving five ethics committees in Colombia, three of them shall notify, in writing, their ethical decisions and opinions regarding the problems proposed in consultancy [16]. According to this information, the importance of proper record of consultancies becomes evident. Besides allowing the consultants have access to data more completely, they can document their responses to the entire care team involved, enabling the monitoring of the patient from health care.

The most common reasons which led to the request for consultancy were decisions involving palliative care, refusal of blood transfusion; relationship between family and care team; diagnostic reporting, and the absence of family for the decision making.

The reports of the consultancies have identified some demographic data of the 84 patients. Regarding gender, 40 (47.62%) were males and 44 (52.38%) females. It was possible to identify the age of 74 patients who presented a high variability, ranging from zero (newborn) to 82 years. The average age was 27.69+23.94 years. Dividing the patients by age, we found that adults aged between 18 and 59 years old demanded 31 consultancies (41.89%). The children, with ages from zero to 11 years old, had 23 consultancies (31.08%). The teenagers, with ages from 12 to 18 years old, and the elderly, aged over 60 years, had similar demands, each group with 10 consultancies (13.51%). Regarding the aforementioned characteristics, other bibliographical sources also allow to demonstrate the agreement regarding the distribution balanced by gender [17] and predominance of adult age [18].

The origin of 68 (80.95%) patients was identified in the records. Porto Alegre is the most frequently cited city, with a frequency of 37 patients (54.41%). 21 patients live in Greater Porto Alegre (30.88%). The remaining 10 patients are from other cities from Rio Grande do Sul (14.71%). From the 66 patients whose electronic health records were identified, 12 were outpatients (18.18%). The remaining 54 (81.82%) were hospitalized at the time of the request for consultancy. The observed distribution is also similar to the which one described in two other studies. In both, there was a predominance of patients from the town itself in front of other sources [19,20].

Considering only the 54 patients in the hospital, 36 were medically discharged for home (64.81%), 11 were discharged due to death (20.37%), three were discharged due to withdrawal of treatment

(5.55%), contrary to the medical indication, one was discharged because of transferring to another institution (1.85%) and two were with incomplete records of discharge in the charts (3.70%). Only one (1.85%) patient remained hospitalized at the time of data collection for this study, conducted in the first semester of 2012. The mortality rate of HCPA is about 5%. Comparing this value with which one obtained in consultancies, which was 20.37%, the seriousness of the cases referred to the discussion of bioethical issues is emphasized. In a study conducted on consultancies carried out in an American intensive care unit, this frequency was 40% [7]. It is worth remembering that patients from all care units were included in the sample studied in HCPA, in different degrees of severity. It is not possible to identify, with the data currently available, the degree of influence of these consultancies on bioethics in these outcomes.

From the 116 records of consultancies, it was possible to identify which family members were involved in 96 cases (82.76%). The family bonds were classified according to the type of relationship, whether naturally imposed, if they were freely chosen, or both. In 76 consultancies, only the relations naturally imposed were identified (65.52%). These relationships include those by consanguinity, such as parents, grandparents, cousins, uncles, sons, brothers, and those chosen by other family members as parents' partners, husbands and wives. On 13 consultancies (11.21%), only relationships of free choice were cited. These relationships include stable partners, boyfriend or girlfriend, and spouses. In seven consultancies, both types of these relationships were identified (6.03%). In the 20 other consultancies (17.24%), the familiar term was generally mentioned without defining the relationship type.

Considering the family relationships indicated in the consultancies, there was agreement with data reported in other studies which characterize the links related to assisting care [21,22]. These data report that family members involved in patient care are those who have relations naturally imposed, i.e. predominantly the bonds of consanguinity. The values oscillate around 70%.

Regarding the number of consultancies evaluated, which totaled 116, these are only part of the activity carried out by the Bioethics Service in these two years. This amount is substantial, especially when compared with those recorded by other institutions, such as the five Colombian ones evaluated, from which three reported that no consultancy was given over a year, another reported that were performed from one to two consultancies per year and, finally, another one reported that evaluates more than 10 cases per year [16]. Other studies have evaluated larger amount of situations, such as the one which carried out 255 consultancies during the period of ten years [7] and another one which gave 285 in three years [17]. For comparison purposes, it should be used the total number of consultancies recorded in HCPA, which totaled 307 in a period of two years – which corresponds approximately to a consultancy every two days.

Final Considerations

Based on the data obtained in this study, it is possible to establish the following profile of consultancy in which the family relationships hindered the resolution of the problem or ethical conflict:

a) The doctors, followed by the nurses, are the people who most demanded consultancies;

b) The specialties of Internal Medicine, Pediatrics and Psychiatry were the most associated ones to consultancies;

c) The medical records, which predominated in the sample, allowed the recovery of information and monitoring of outcomes associated to consultancies requested;

d) The patients involved in consultancies were predominantly adults, coming from the city itself where they were hospitalized and were discharged to home care. Regarding gender, the distribution between men and women was balanced;

e) The families relationships naturally imposed, especially the ones of consanguinity, are the most involved ones in situations of consultancy.

These data, associated to the realization that there are few studies characterizing consultancies of clinical bioethics, and fewer still, those involving patients' families, emphasize the importance of further studies need to be conducted in order to enable a proper understanding of ethical problems and their possible resolutions, including an evaluation of the impact of interventions carried out. It should be noted, moreover, that such studies may stimulate the implementation of instances focused on bioethical reflection in other institutions or enhance existing services, contributing also to consolidate the hall of practical examples which can be discussed and worked during the professional training.

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