

Empirical studies on Healthcare Ethics Committees in the USA. A Bibliographic review

Salvador Ribas Ribas, Ph. D.

Faculty of Philosophy, University of Roman Lull, Spain

INTRODUCTION

The historical precedents of Healthcare Ethics Committees (HEC) date back to the 60's and 70's in the United States of America (USA). The need to create ethical consultation services in hospital centers was due to a number of cases that arose primarily as a result of the scientific and technical advances in biomedicine and specifically in habitual clinical practice. The first of these appeared in Seattle in 1961, where a technological breakthrough appeared in hemodialysis to treat patients with renal failure (Rescher, 1969).

However it wasn't until the 80's and beginning of the 90's that different american organizations acknowledged the need for ethics committees in hospitals and other care centers (President's Commission, 1983; American Hospital Association, 1984; American Medical Association, 1985). The appearance of reports and recommendations in favor of the existence of ethics committees, publicly declaring the need for them in hospitals, was a great help for their establishment in the US. However, the definitive impetus leading to ethics committees becoming commonplace in hospital centers was the hospital accreditation manual of 1992 from the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). That year, the commission included as a quality criterion for all hospitals the possession of some "mechanism" to help health professionals, patients and families tackle the ethical conflicts that may arise during the healthcare process (JCAHO, 1992).

During these last 20 years of HEC, many have debated the capacity and professional profile to be held by those forming part of a committee. Concerning the figure of the ethics committee professional, in 1998 the work group of the Task Force on Standards on Bioethics Consultation, coordinated by the Society for Health and Human Values and the Society for Bioethics Consultation, published the report entitled Core Competencies for Health Care Ethics Consultation (American Society for Bioethics and Humanities, 1998), proposing criteria to guarantee the capacity and quality of so-called Ethics Consultation Services.

In the USA there is currently no database with information on the composition and operations of HEC. The main aim of this metaanalysis is to analyze the descriptive

and evaluative data given by retrospective studies focusing on HEC, based on a review of the literature, in order to discover their current status in the USA.

Methodology

The bibliographical review, carried out by a sole reviewer, was made up of three stages: article search and selection; data mining; and analysis of the results obtained in the cases where this is appropriate. The bibliographical search was based primarily on bioethical and biomedical journals, using two databases: the Ethx database, linked to the National Referenceo dao dao dao dao dao dae ¹. Advanced search programs were used to look for articles with the Boolean variables available in each of the databases. Moreover, the key words were also adapted to the search strategies used in both cases. The key words used for the initial search, chosen by the researcher, were “ethics”, “consultation”, “committees”, “evaluation study” and “descriptive study”. And in the additional exploratory search, the following key words were also used: “survey”, “statistic”, “analysis”, “success” and “effectiveness”.

Additionally, another two bibliographical sources were used: firstly, the LocatorPlus database was accessed to search for possible information documented in books and, secondly, other published reviews predating this study were also consulted (Pruzinsky, 1989; Tulsy and Fox, 1996; Darragh, 1999). Lastly, an ascending search was carried out based on the pre-selected articles, completing the systematic search.

As a unique inclusion criterion, the articles resulting from the bibliographical search had to contain descriptive and/or evaluative data on ethics committees or consultants located in the US. After this pre-selection, the studies were chosen and three main aspects of a methodological nature were taken into account for their definitive inclusion in the review: the justification, the study design and the analysis and results of the data reported. Regarding the justification and aims of the study, their clarity and feasibility were considered. With regard to design, the socio-demographic and geographical characteristics of the samples were taken into account (age and gender of the subjects studied, participating centers, etc.) and the description and validity of the instrument used such as questionnaires, focus group techniques, etc. Thirdly, the type of analysis and the measurement of the results of each study were also considered.

Two groups were basically differentiated in order to mine the data: one regarding the articles and the other regarding the studies. After collecting the bibliometric data, a descriptive analysis was carried out of the frequency distribution and contingency tables among the most significant dimensions to analyze the correlation between them. All these analyses were carried out with version 10.0 of the SPSS program.

After reviewing the studies, the data reported were classified into two groups: descriptive and evaluative. Only the most representative data were selected from all those

obtained from each article. Data were also analyzed on the effectiveness and the perception held by physicians, patients and families concerning ethics committees.

Findings

After the bibliographical search and pre-selection of articles a total of 58 articles were chosen, of which access was secured to 52, covering data from a total of 48 studies. An analysis of the data contained in some studies confirms the growing interest in HEC in the USA, given that the number of journals in the 90's is double that of the 80's. This increase can also be seen in the number of studies providing both descriptive data and those containing evaluative data. However, there seems to be a growing interest in obtaining data that permits an evaluation of HEC (see Table 1 and 2).

Furthermore, the interest in HECs is generally multidisciplinary and 71% of the publications are by more than one author, be they articles published in bioethical or medical journals. Both in the discipline of Medicine and Bioethics articles related to ethics committees are well accepted for publication: of the 52 articles selected, 44% of them are published in Bioethics journals and 46% in Medicine journals (Table 1). And with reference to the quality of the articles published, the great majority has an acceptable level of scientific evidence, with an average of 16.75 bibliographical quotes per publication. However, only 15% of the articles have key words although, on the other hand, over half (55%) contain a summary (see Table 3).

The number of studies included is located, with very similar percentages, in the local and national sphere: 22 (45.8%) are local studies and a little more than 50% (n=26) of the studies are national. The difference lies in the type of information reported by the studies. While 90% (n=43) of the studies contain descriptive data, only 24 cover evaluative data. And regarding the sample size, a total of 20 studies (77%) were carried out with fewer than 1,000 subjects, while only 6 of the studies contained a sample greater than 1,000 participants. In the first group, the average reply rate was around 75%, while in the studies with a larger sample the rate was only 29% (see Table 1).

Regarding the number of HEC existing in the US, their rise in the last two decades is considerable. Whereas only 2% of hospitals had an ethics committee in 1983 (Youngner et al., 1983), it is estimated that over 90% of hospitals now have one (McGee et al., 2002). In spite of this, the percentage of HEC in existence is not the same for all hospital centers. For example, the presence of ethics committees in long-stay centers and mental hospitals is lower in comparison with other hospitals. According to data from a recent study, of a sample of 334 centers with an ethics committee only 2% were in long-stay centers while the remaining 83% were hospitals (Schick and Fache, 2001). Furthermore, in another previous study (Jurcak, 1998), 94% of a sample of 289 ethics consultants belonged to hospitals and only 2% provided services in long-stay centers.

On a different note, the findings obtained estimate that an ethics committee is made up of approximately 12 to 16 components (McGee et al., 2002; Hoffmann et al., 2000; D'Oronzio et al., 1991), physicians and nurses being the groups with greatest presence in HEC with an average of 4 to 6 members. These are followed by the lower percentages of the clergy, social workers, administration representatives, bioethicists, citizen representatives and law professionals, es, es, es, es, es, es, es, es, es, rs per committee. The preeminence of physicians can be confirmed in the data from studies by Skeel and Self (1989), and Scheirton (1992). In a survey carried out on a total of 525 clinical ethicists, 35% (n=113) had Medicine as their basic training, while just 21% and 15% came from the disciplines of Technology and Philosophy, respectively (Skeel and Self, 1989). And in another survey on professionals presiding over HEC, more than 77% of the total sample were physicians and only 6.6% bioethicists (Scheirton, 1992).

However, and in spite of the differences between both groups, there seems to be an increasing acceptance of the second group as reported by some studies (see Figure 1). The presence of physicians has been maintained since the beginning, while the other professionals, to a greater or lesser degree, have increased their representation in comparison with the initial data indicated by Youngner et al. (1983).

Regarding the ethical conflicts usually handled by the HEC, the most repeated subjects are: continuation or not of a treatment and futile treatment, the appropriateness of cardio-pulmonary reanimation, and the autonomy and capacity of the patient to decide. On the other hand, ethical conflicts are not of the same type in all hospital centers. For example, in mental hospitals the most common conflicts are those concerning informed consent and the right to know (Backlar, 1993). In infant maternity hospitals, the most common cases are those in which there are congenital abnormalities (Edens, 1990) and also when a limit to treatment is being considered. This second group, according to the data reported by Orr and Perkins (1994), account for 91% of the cases in these centers. And, lastly, in the long-stay centers there is a prevalence of conflicts regarding cardio-pulmonary reanimation, accounting for 80% of all cases usually presented before a committee (Glasser, 1988).

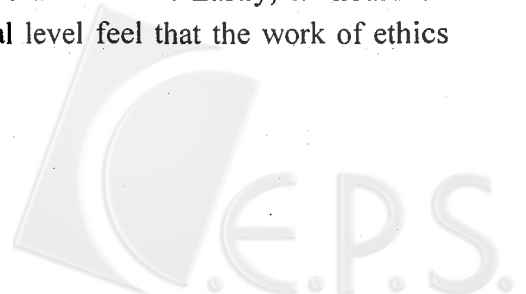
With respect to the evaluative data reported by the studies, the indicators identified in order to evaluate HEC may be grouped into two dimensions: one relating to the reports of the activities carried out by the committees and the other relating to the perceived usefulness and effectiveness of the committees. As a result, the first dimension concerns which tasks a committee carries out and the second how it carries them out. Regarding the first of these two dimensions, the most common items usually considered in the course of one year when evaluating a committee are: the number of cases considered (retrospective and prospective), the drawing up of recommendations, the training programs and number of training courses and the frequency of committee

meetings. And regarding the usefulness and effectiveness of HEC, the most widely used method is usually satisfaction questionnaires, in most cases using Likert scales. The most frequent questions identified in the studies regarding the usefulness of an ethics committee are: the ethics committee, has it helped you understand subjects of an ethical nature better?; to identify new ethical conflicts?; in your Ethics training?; in decision making?; throughout the care process of a clinical case?; to get more information?; to help patients and relatives emotionally?; and, lastly, to improve communication and resolve disagreements between physicians, patients and relatives?.

On analyzing the evaluative indicators the findings are positive. In general, physicians, nurses, patients and relatives consider that ethics committees are necessary in hospitals. This is demonstrated by the data contained in the studies of Youngner et al. (1984) and, years later, Finkenbine and Gramelspacher (1991). In the first study, 76% of the people interviewed felt that ethics committees could be useful while only 4% thought the opposite. For its part, in the Finkenbine study, which analyzed a sample of 618 health professionals, 87% saw the need for ethics committees in hospitals.

The findings are also promising regarding the usefulness and effectiveness of HEC. In one of the first studies at a national level (Youngner et al., 1983), the professionals were asked which tasks, in their opinion, the committees could assist with. 73% of the participants felt that the main use of ethics committees was in identifying ethical conflicts in a clinical case, 60% thought that HEC could help handle aspects of a legal nature and 47% of those who answered the survey believed that a valuable function of hospital committees would be to focus on finding resolutions to disagreements between physicians, nurses and other health professionals. Of these three functions, the first is the most widely acknowledged, as shown by the data reported by Orr and Moon (1993) ten years later, in which 74% of the physicians interviewed felt that one of the most important tasks of HECs is identifying and clarifying ethical conflicts that may arise in habitual clinical practice.

Finally, and after recoding the values reported by the satisfaction surveys (McIntyre and Buchalter, 1984; Scheirton, 1993; Fletcher et al., 1990; McClung et al., 1996), the perception of professionals regarding the operations and effectiveness of HECs achieved an average of 79.27 points out of a scale of 100. For its part, the satisfaction perceived by patients and families (McClung et al., 1996; Orr et al., 1996) was 73.5 points, somewhat below that perceived by physicians and nurses. Lastly, it should be noted that 75% of medical organizations at a national level feel that the work of ethics committees is highly valuable (Domen, 1995).



Discussion and conclusions

There were three significant factors that hindered the obtaining of findings in the systematic search and selection of articles: (a) the shortage of key words and summaries in articles; (b) the absence of an instrument to measure the quality of the published works; and (c) the diversity of the variables covered by the studies.

The fact that a total of 19 different key words were found in a total of 8 studies, as well as the low percentage of studies containing key words, are indicators of the scant consensus on how to catalogue Bioethical works. Bioethical discourse covers a large number of subjects and all of them of a diverse nature. This is one of the reasons why it is difficult to classify the articles in databases such as Medline. Without any doubt, the fact that a Bioethical article possesses key words facilitates the bibliographical search for studies and permits a fast location of the subjects covered, although this also entails some risks. On the one hand, classifying a work with one or more terms means limiting the usefulness of this article, so that it is restricted to dealing only with the subjects referenced by means of its key words. Furthermore, if very generic terms are used, such as "hospital ethics committees" or "physician-patient relations", these also contain a myriad of other specific subjects such as, for example, confidentiality, informed consent, etc.

Certainly subjects that are the object of study in the discipline of Bioethics cannot nor should not be treated unilaterally. But in spite of this, given the large volume of publications it seems advisable to use key words to facilitate an initial location and classification of the subjects. An effort to standardize and identify the areas dealt with by Bioethics is the task carried out by a work group of the National Reference Center for Bioethics Literature, which has drawn up an index with a total of 22 thematic groups. For bibliographical search strategies, the NRCBL initiative is a good complement to the already existing Medical Subject Headings (MeSH) of the Medicus Index, enabling and providing bioethical work with greater scientific evidence.

The absence of an instrument or scale of measurement to evaluate the quality of the studies found and to provide criteria for their inclusion or exclusion has been another deficient factor in this review. It was decided to use generic methodological criteria in order to include or exclude studies in this review. For future bibliographical reviews, it would be advisable to have some kind of instrument for measuring the quality of the articles. The fact that an article is published in a journal with a high impact factor or that it appears indexed in databases such as Medline or Ethx may certify, to a certain extent, the methodological quality of the study, without this being considered as a unique indicator of quality. The care in the design of the study or the methodology in the analysis of the data are other essential elements to be taken into account, since the degree of validity of the findings and their subsequent interpretation depend on these factors.

And, lastly, a third element that has made this review difficult was the plurality of variables covered by each study and the way in which they were reported. Variability in the sampling (for example, the ranges in sample size, the socio-demographic data, etc.), in study design and also in data reported has not permitted a comparative analysis to extrapolate of results. For future studies, a consensus would therefore be recommendable, not only in how findings are presented but also in presenting the sample data for empirical studies in bioethics.

On viewing the findings, it has been confirmed that the presence of ethics committees is currently somewhat habitual in hospital centers in the US and that, furthermore, interest in these bodies is generally high if we observe the increase in the number of journals. Furthermore, the existence of HEC does not only respond to the fear of losing the JCAHO accreditation, as a response to the Federal regulations, or simply because it is fashionable to create committees, but also because they are quite necessary and of use to physicians and patients in helping them resolve ethical conflicts. In spite of this, however, the proliferation of ethics committees and ethics consultants in hospitals is not exempt from criticism (Scofield, 1993; Levine, 1984; Siegler, 1986; Lo, 1987; Leavitt, 2000; Spike and Greenlaw, 2000).

The main drawback usually attributed to HEC is the interference they could represent in the physician-patient relationship, as well as their influence on patient preferences. Another criticism is the image that they may occasionally give, which is, according to the words of B. Lo (1987), a "groupthink", i.e., like a group of experts who tend to impose their particular moral concept and values. And this is even worse when an individual is not a group but an individual under the flag of the supposedly "expert voice" since, on the one hand, their participation in a committee can impede the initiative of the other members and, on the other, ethics consultants should not be seen as the "answer person" or the one who provides solutions to all problems (Skeel and Self, 1989). The fact that a person has greater knowledge regarding ethical theories or bioethics in general does not, as a rule, give them moral authority but neither is it a reason to undervalue their opinion as an expert.

After analyzing the data, the findings do not permit a real estimation of the number of hospitals that currently have individual ethics consultants. In a survey carried out on a total of 117 members of the SBC, 81% (n=95) of the sample had belonged to an HEC, while 62% (n=72) had acted on some occasion as individual consultants in hospitals (Fox and Stocking, 1993). The data obtained by Fox and Stocking cannot be extrapolated at a national level, although it does lead to the suspicion that the presence of committees or consultants in hospitals in the US is very similar. Currently, and based on the literature, three broad models may be established that are defined by ASBH as Ethics Consultation Service: (a) the individual; (b) the committee; and (c) the mixed model

(Siegler, 1986; Swenson and Miller, 1992; Brennan, 1992; La Puma and Toulmin, 1989; American Society for Bioethics and Humanities, 1998). The shortage of information reported by the studies does not permit an evaluation of the effectiveness of each of them nor a comparison between them. In any case, whether individual consultants or committees, we believe that an Ethics Consultation Service must adapt to the organizational environment. The physician-patient relationship takes place within both a care and organizational framework. The management of resources or healthcare organizational changes, such as home care, is something that affects everyone and cannot be ignored by ethics committees. That is why it seems logical to maintain that future models of Ethics Consultation Service must adapt themselves to continuous organizational changes, without forgetting, however, that the "the moral heart of an ethics consultation - writes Pellegrino - as of any clinical consultation, is the improvement of the care of patients" (Pellegrino, 1990).

Given the increase in the presence of HEC in hospitals in the US, it seems quite necessary to be able to evaluate them order to guarantee the quality of their services (Hoffmann et al., 2000; La Puma and Schiedermayer, 1991; Griener and Storch, 1992; Howe, 1999). The diagnosed "failure to thrive" syndrome (Fletcher, 1997) is a clear indication that the important thing now is not so much to create ethics committees but to guarantee their continuity and quality since, as C. Levine rightly noted, "their presence - that of committees - does not guarantee that they will be used constructively [...]" (Levine, 1984).

The increase in the number of studies providing evaluative data is a clear indication of the interest and concern for the continuity of HEC. However, there a consensus still seems to be lacking concerning which items must be considered when evaluating an HEC. In general, data are usually reported such as the number and frequency of committee meetings or the number of cases dealt with. These data can give an idea of the activity of committees but are not valid indicators of the quality of the activities carried out by the committee. In effect, as Scheirton writes: "a committee that writes a dozen guidelines on all possible ethical dilemmas during a decade, organizes some 100 educational programs every year and conducts a consultation every other day may not be truly effective from an ethical point of view" (Scheirton, 1993).

Actually, it is clear that as a Fletcher and Hoffmann write 10 years ago "the time for a laissez faire approach to ethics committees is long past" (Fletcher and Hoffmann, 1994), and that standard criteria to guarantee the quality of HEC is now essential. Several methods for evaluating HEC have been proposed in the literature (Anzia and La Puma, 1992, Leeman et al., 1997) and, for the continuity and evaluation of ethics committees, it would be recommendable to direct efforts to achieve a consensus on the standard criteria used to measure the quality of HEC and ethics consultation services.

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Figure 1. Evolution of representation by professional category on HECs

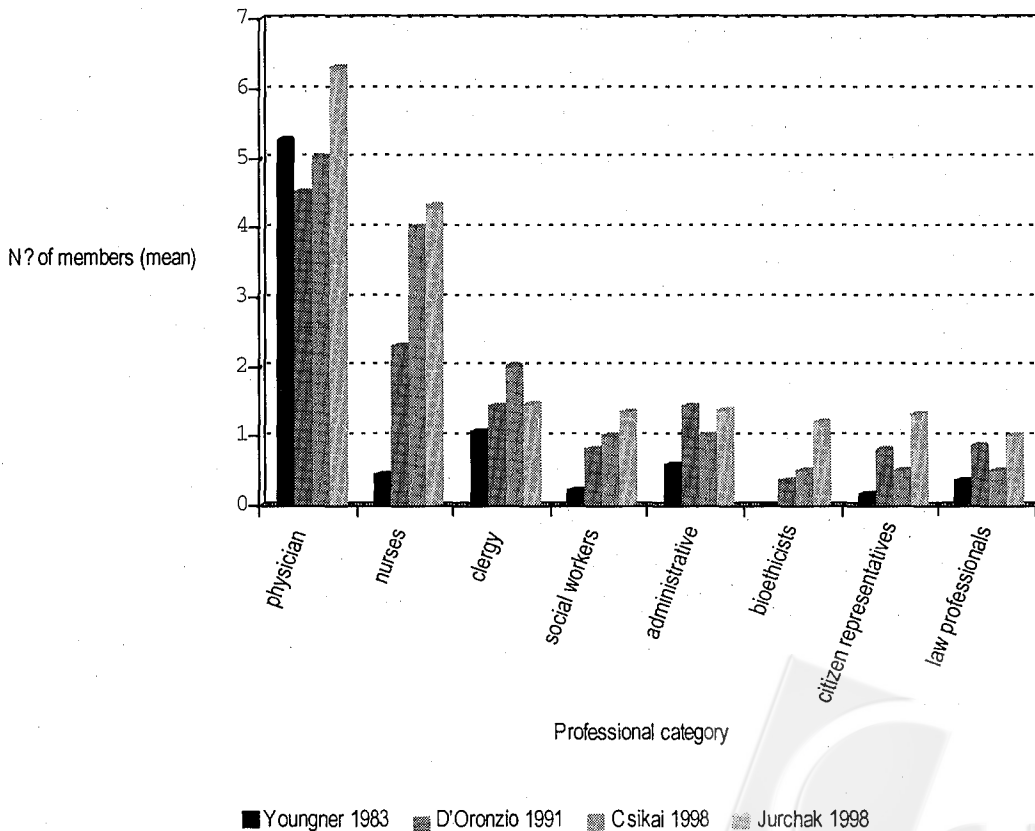


Table 1. Basic traits of empirical studies

Basic traits of empirical studies Sample = 48		N (%)
Geographic area	National*	22 (45.8%)
	Local**	26 (54.1%)
Type of data reported	Descriptive data	43 (89.5%)
	Evaluative data	24 (50%)
Sample size **	> 1000 [Range=1000-4829]	6 (23%)
	< 1000 [Range=7-1000]	20 (77%)

* National level includes those studies performed in one or more states or in which the sample was obtained from nationally-based associations or organizations. Local level includes studies performed in one single healthcare ethics committees, hospital, or other health care institution.

** Percentage calculated for studies in which sample size details were provided (n=26).

Table 2. Type of projects vs. publication period

Studies reporting data...	Publication period	
	N (%)	
Sample = 48	1981-1990	1991-2000
Descriptive data	15 (31.2%)	22 (45.8%)
Evaluative data	6 (12.5%)	17 (35.4%)



Table 3. Bibliometric traits of publications

Bibliometric traits Sample = 52		N (%)
Publication period	1981-1990	18 (34.6%)
	1991-2000	31 (59.6%)
	2001-2002	3 (5.7%)
Type of journal	Bioethics	23 (44.2%)
	Medicine	24 (46.1%)
	Others	5 (9.6%)
Authors	1 author	15 (28.8%)
	≥ 2 authors	37 (71.1%)
	Mean and range	2.5 (1-7)
Bibliographic references	10-20	15 (28.8%)
	> 20	18 (34.6%)
	< 10	19 (36.5%)
	Mean and range	16.75 (0-52)
Articles with ...	Abstract	29 (55.7%)
	Key words	8 (15.3%)