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SOMMARIO

Establishing and coordinating a regional network of healthcare ethics committees. Findings and lessons learnt from a qualitative research in the Veneto Region (Italy)

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ABSTRACT

While research ethics committees (RECs) are well established and widespread all over Italy, self-standing healthcare ethics committees (HECs) are relatively rare. A notable exception is the Veneto Region, where the Regional Government has promoted the creation of a network of over 20 HECs since 2004, serving a population of approximately 5 million inhabitants. This remarkable undertaking has not, however, been studied yet. To fill this gap, four focus groups (FGs) have been designed and carried out to investigate the opinions of expert HEC members as to the way HECs operate, the relevance of the work performed by the committees, and their most important needs in order to improve the quality of the services they provide. The qualitative content analysis has led to the identification of three main recurrent themes, which are presented and critically discussed, since they may be relevant for similar networks: 1) a dichotomy between the perceived importance of the ethics committee by HEC members and the widespread scepticism or indifference among healthcare professionals; 2) a lack of homogeneity among committees, as to their main activity, their relationship with the management of the hosting institution, and the way HEC members are recruited; 3) the awareness that these HECs need stronger coordination and support. After proposing an interpretation of these main themes, we conclude by giving recommendations to healthcare institutions wishing to set up a network of HECs with the aim of rooting and straightening ethical reflection within the healthcare setting.

RIASSUNTO

Creare e coordinare una rete regionale di comitati etici per la pratica clinica. Risultati e lezioni apprese da uno studio qualitativo svolto in Veneto.

Mentre i comitati etici per la ricerca sono diffusi in tutta Italia, comitati etici esclusivamente dedicati alla pratica clinica sono piuttosto rari. Un'eccezione significativa è costituita dalla Regione Veneto, ove il governo regionale ha promosso fin dal 2004 la creazione di una rete di oltre 20 comitati etici per la pratica clinica (CEPC), al servizio di una popolazione di circa 5 milioni di abitanti. Questa notevole esperienza, tuttavia, non era stata finora studiata. Per colmare tale lacuna, sono stati progettati e realizzati quattro focus group (FG), al fine di indagare le opinioni di componenti esperti di questa tipologia di comitati, relativamente al modo in cui operano, alla rilevanza del lavoro svolto dai CEPC e ai bisogni da soddisfare per migliorare la qualità del servizio. L'analisi qualitativa di quanto emerso dai FG ha portato all'identificazione di tre temi principali, che sono presentati e discussi, vista la rilevanza che potrebbero avere per simili reti: 1) una dicotomia tra la rilevanza dei CEPC, sperimentata

dai componenti dei comitati stessi, e lo scetticismo che circonda questi organismi; 2) una mancanza di omogeneità tra comitati, sia in merito alla loro attività principale, sia rispetto al loro rapporto con la direzione e al modo in cui sono selezionati i componenti; 3) la consapevolezza che i CEPC hanno bisogno di coordinamento e supporto. Dopo aver proposto un'interpretazione di questi temi, vengono offerte alcune raccomandazioni alle istituzioni sanitarie che volessero istituire una rete di CEPC che contribuisca a radicare e rafforzare la riflessione etica all'interno del mondo sanitario.

Key-words: healthcare ethics committees, clinical ethics committees, clinical ethics networks, ethics consultation, qualitative research, focus group.

Parole-chiave: comitati etici per la pratica clinica, reti di etica clinica, consulenza etica, ricerca qualitativa, focus group.

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1. Background

As in most parts of the world, research ethics committees (RECs) are well-established all over Italy. Since the early '90s, RECs have been regulated by law and have been instrumental in approving clinical trials. On the contrary, Healthcare Ethics Committees (HECs) are neither clearly regulated nor mandatory. Consequently, they are not uniformly widespread, and in most cases their typical functions are added to the duties of the existing RECs, which generally do not have the time or the competences to adequately perform them.

A notable exception to this situation is the Veneto Region – with a population of approximately 5 million inhabitants – where in 2004 the Regional Government promoted the generalized establishment of HECs as self-standing committees. Before that date, few HECs existed in Veneto. These pioneering experiences, though commendable, were not coordinated, but rather were the result of spontaneous initiatives by forward-thinking individuals.

As anticipated, in December 2004 the Regional Government decided to reorganize bioethics services in the Region. To that aim, it designed a network of bioethics committees (see *Table 1*) made up of one Regional Bioethics Committee, 11 RECs and 26 HECs. Assigning the tasks of evaluating research protocols and that of tackling clinical ethics issues to two different kinds of ethics committees was the innovative decision, and it was in line with the recommendations of Italy's National Bioethics Committee [1] – recently updated [2] – and with best international practices. As

Table 1
The Veneto Region Network of Bioethics Committees as designed by the Regional Government Decree 4049/2004

Type of Ethics Committee	**Regional Bioethics Committee**	**Research Ethics Committees**	**Healthcare Ethics Committees**
Nr.	1	11	26
Tasks	• advice to the Regional Government on bioethical issues • promotion of bioethics awareness among the general public • coordination of the regional network of ethics committees	• ethical analysis of research protocols	• ethics consultation • policy work • bioethics education

It must be noted that recent changes have brought to a reduction of the number of both RECs (which are now 6) and HECs (which are now 14). However, the overall structure of the network of bioethics committees has not been altered.

a direct result of this top-down input, in the following ten years over 20 new HECs were established, creating a network rivalled by few others in Europe.

Surprisingly, this remarkable entity has not been properly studied and evaluated yet, as is normally the practice in Western Europe in the case of similar networks, such as those of Norway [3-6], the UK [7-9] and Germany [10]. To address this gap in the literature, the University of Padova has promoted a research project to study the Veneto network of HECs. The importance of this research for the future development of the network was recognized by the Regional Bioethics Committee, which facilitated its realization.

2. Method

In order to explore how the Veneto Region HECs network functioned during its first decade, it was clear from the beginning of the project that quantitative data would not be adequate to understand the experience in depth. The focus group method was considered the most suitable to investigate perceived strengths and weaknesses of the HECs, as well as successes, problems and needs. Such qualitative methods have indeed been already employed for similar projects with regard to HECs [11-13].

2.1. Sampling and recruitment

Selection criteria were set to establish that FG participants had sufficient expe-

rience and could represent the composition of a standard HEC. FG participants:

- should come from as many HECs operating in the Region as possible (two members per committee; the two participants from the same HEC, however, had to take part to different FGs);

- should have at least 3 years of experience within a HEC;

- should be representative of the various professionals and of the lay figures serving in a HEC;

- should be balanced as much as possible in terms of gender.

Of the 24 committees active at the moment of the selection of the FGs participants, two didn't meet the selection criteria (they were too "young", i.e. they had been active for less than three years). Of the remaining 22 HECs, 18 accepted to take part in the study (81,8%) and sent 36 members in total to the FGs. *Tables 2* and *3* summarize the main characteristics of FG participants, regarding sex, age, experience wi-

Table 2
Composition of FG and characteristics of FG participants

	Nr. of Participants	Males	Females	Average age	Average experience within a HEC
Focus Group 1	8	5	3	61,50 years	6,62 years
Focus Group 2	7	5	2	55,14 years	6,28 years
Focus Group 3	10	2	8	57,00 years	6,20 years
Focus Group 4	11	4	7	55,54 years	6,45 years
Total Nr. (%)	**36** (100%)	**16** (44,5%)	**20** (55,5%)	**57,19 years**	**6,39 years**

Table 3
Distribution of FGs participants per profession (or role) in the HEC

Profession (or role) in the HEC	**Nr. (%)**
Physicians	**15** (41,6%)
Nurses and other healthcare professionals	**7** (19,4%)
Psychologists	**5** (13,9%)
Bioethics experts	**3** (8,3%)
Law experts	**2** (5,6%)
Representatives of the general population (lay members)	**2** (5,6%)
Social workers	**1** (2,8%)
Theologians / Pastoral care experts	**1** (2,8%)
Total	**36 (100%)**

thin a HEC and their distribution per profession (or role) in the committee.

Gender balance was achieved in the overall composition (16 males, 20 females), though not always within each FG. Duration of experience working within a HEC was very high (in average, 6,39 years), ranging from 3 to 18 years. The average age of FG participants was rather high (over 57), ranging from 35 to 80.

As to the profession (or role played within the committee), we were able to reproduce, overall, the composition of an "ideal" HEC, according both to regional regulations and international standards [14-17]: physicians were the majority subgroup (over 41%), yet less than 50%. Nurses and other healthcare professionals made up for 1/5 of the group. Experts in psychology, bioethics, law and theology were also present, along with two representatives of the general population.

2.2. Data collection and analysis

The four FGs were moderated on the basis of a pre-agreed interview guide by two psychologists who, when needed, asked probing questions. The two psychologists had extensive experience as FG moderators, as well as in the bioethics field [18]. Each FG lasted about two hours and was both video and audio recorded. All FG participants were informed about the method and the aims of the study, and that the FGs would be recorded. They were assured that privacy was guaranteed. Furthermore, they all signed an informed consent form.

The interview guide, jointly developed by the authors with the consultation of the then chair of the Regional Bioethics Committee, focused on three main areas: 1) *current HEC practices* (main activities, ways of performing such activities, relationship with the management of the healthcare institution, etc.); 2) *evaluation of the experience* (relevance of the HEC work for the committee members themselves, perception of HEC relevance by the healthcare institution and by the general population, barriers and challenges in performing their tasks, etc.); 3) *needs and proposals for future development* (educational and material needs, suggestion for enhancing the network, etc.). The FG records were transcribed, and the transcripts were checked independently by two reviewers.

As to the analysis, each of the four authors (two bioethicists and the two FG moderators) performed an independent qualitative content analysis [19; 20]. After a first reading to form a general impression, a second reading resulted in a preliminary identification and categorization of the central themes. In a subsequent phase, the FG moderators, who did not have any personal experience of HECs, compared their preliminary analyses and notes. The bioethicists, who on the contrary had experience within HECs but didn't take part in the FGs, did the same. This protocol was aimed, on the one hand, to grant a fresh look at the opinions of HEC members, and on the other hand to make sure that such opinions were checked and interpreted, also benefiting from the perspective of someone with direct experience of HECs and with previous studies of the topic [21; 22]. Finally, the various preliminary categorizations and interpretations were compared, critically discussed

and reviewed by all four authors, until agreement was reached.

3. Results

The qualitative content analysis resulted in the identification of three main themes:

1) a dichotomy between the perceived importance of the ethics committee by HEC members and the scepticism or indifference among many healthcare professionals, especially doctors;

2) a noticeable lack of homogeneity among committees, regarding at least three aspects: a) main activities; b) relationship with the management of the nominating institution; c) way HEC members are recruited;

3) a shared awareness that a network of HECs requires continuous institutional support in order to thrive, or it risks gradual decline.

3.1. Dichotomy between perceived importance and widespread scepticism

The first and most recurrent theme that emerged during the FGs is what can be described as a painful dichotomy. On the one hand, the vast majority of these HEC members referred to their experience within the committee as extremely rewarding, professionally enriching and even life-changing:

> This experience completely changed the direction of my activity as a physician, it radically transformed the attitude toward my work. (*physician*)

> Being part of the committee makes you reflect on aspects of your life and work you didn't even consider before. You start posing yourself questions you had never asked. (*nurse*)

> The participation in the HEC activities changes not only your professional life, but more importantly your culture, your mentality. It opens up your mind towards the others and provides you with a new way to approach problems. (*physician*)

On the other hand, virtually everyone reported the disappointing fact that the committee itself and bioethics in general are considered by many healthcare professionals with great scepticism, if not simply ignored. This is especially true for physicians, who rarely require the committee advice and seldom show up to bioethics education events:

> Physicians are the first who do not believe in the need to ask for ethics advice. Many colleagues tell me: "Listen, the ethical thing to do is to provide good care. That's it". It seems that it never crosses their mind a doubt about what "good care" is, in certain complicated and unprecedented situations. (*physician*)

> When I tell my colleagues that I'm going to the ethics committee meeting, most of them think or say: "Good for you: some nice free time! You don't accomplish anything, you just chat". This is a widespread belief, and that's why I spend a lot of time trying to explain that bioethics is fundamental now and that it is going to remain fundamental in the future to come. (*physician*)

Other healthcare professionals, especially nurses, as well as the general population (e.g., secondary school students involved in bioethics education activities), seem to be much more receptive. However, all FG participants had the clear impression

that most citizens do not know either that HECs exist, or what their functions are and how they can be consulted:

> I think there is a great need for ethics consultation, yet very few people are aware of the existence of the committee: both healthcare professionals and patients or their families do not know that they could resort to such a service. (*psychologist*)

In sum, most FG participants have to deal with a frustrating situation: the experience of how important the ethics committee is for them and for those who get in contact with it; and the discouraging verification that the HEC is still largely unknown or undervalued.

3.2. Lack of homogeneity

A second theme that emerged is the noticeable lack of homogeneity in the way the Veneto Region HECs operate. This is true in the following aspects: a) the activities performed by the committee; b) the relationship with the management of the nominating institution; c) the way HEC members are recruited.

When asked about the tasks most performed by their committee, only few FG participants mentioned ethics consultation on clinical cases as their most important function; most committees discuss just one or two cases per year, some none at all. Surprised by the scant ethics consultation requests, some HECs have also adopted more flexible ways of providing ethics consultation, like the "small team model", with some encouraging results.

As to the second classical function of HECs (ethics policy work), half of the committees have produced ethics policy documents, on topics such as informed consent, enteral nutrition in the case of patients with advanced dementia, and end-of-life decisions. The members of the committees who engaged in such tasks were enthusiastic, especially regarding the concrete impact of these documents on the daily life of the healthcare institution. However, other FG participants questioned the very legitimacy of such activity, arguing that HECs do not normally have the competences and the authority to perform this task.

The only classical HEC function generally performed by virtually all committees is bioethics education (for the committee members themselves, for healthcare professionals and for the general population). Educational activities to sensitize about bioethical issues were considered as crucial. This fact is likely due to the perceived HEC identity by the majority of FG participants, who indicated the ultimate meaning of the committee work in the "humanization" of medicine. FG participants agreed that HECs should fight against the "technical drift" of clinical practice and the so-called "defensive medicine". And ethics education is seen as a powerful tool to that aim.

A second aspect in which the Veneto Region HECs seem to differ greatly from each other is the relationship with the management of the nominating institution. Some committees (about one third of those who participated in the FGs) feel they have good support by the board of directors. In many other cases, however, HECs felt either ignored or not adequately sustained:

> The problems we face are countless. For example, we don't have a secretary: so, how can we take the minutes of our meetings, collaborate with the other committees of the network, answer emails, keep our webpage updated, organize educational events? Not to mention the fact that we do not have a budget. […] Furthermore, in my official schedule, the time I dedicate to the committee is not even indicated as such. This is a sign that this activity is not recognized, that the time devoted to the HEC is not seen as important. (*physician*)

A third and final aspect in which the Veneto HECs differ significantly has to do with the way committee members are recruited. As to this issue, FG participants seem to fall into one of the following three categories: top-down appointment, HEC recommended appointment, appointment after self-application. Appointments of the first category (top-down) were very frequent in the past and are not uncommon at present. This way of appointing new members is considered very frustrating by experienced committee members and it is not without negative consequences:

> Recently, the management has radically renewed the committee, getting rid of some members and nominating others. […] It has been frustrating for at least three reasons: the administration has decided without asking our opinion or if we had any suggestion; they have appointed people without any bioethics education and without explaining the criteria; during the first meetings of the new committee, we often didn't reach the quorum and this is emblematic of the motivation and interest for ethics of these top-down nominated new members. (*psychologist*)

A second approach consists in the collaboration between the nominating institution and the committee itself. In this case, the ethics committee suggests a list of candidates, articulating the reasons for the recommendation (e.g., formal bioethics education, interest and sensitivity to ethical issues, willingness and possibility to invest time) and the management makes the final choice:

> I have been reconfirmed in the new committee to make to most of the expertise developed over the years. It takes time to get educated in bioethics (you need a lot of knowledge). For this reason, some of the "old" members have been reappointed, along with new components, in order not to waste such expertise. (*nurse*)

> We have been very lucky with our administration: we have always had the opportunity to suggest the new members and we have never been obstructed. I believe this is important and should be granted […] Of course, the director have to ratify the recommendation, but the selection of the candidates must be done considering the qualifications and the sensitivity to the topic. (*committee chair, physician*)

Finally, in some cases the appointment in the committee follows the self-proposal by an interested professional:

> I have entered the committee four years ago out of my interest for palliative care. […] People nowadays do not die like in the past and this poses challenges medicine has to face and to think about. […] We have created a home palliative care service and this experience led me almost naturally to the committee. (*general practitioner*)

3.3. Thriving or dying

The third central theme has to do with the future of the experience. Many FG participants seemed persuaded that the net-

work is at a turning point: after being established everywhere in the region, there is a need to systematically connect such committees and to better train their members. When asked about their needs in order to realize such development, FG participants mentioned four key factors: networking, education, innovation and material support.

The first need may seem paradoxical: the network asks for networking! Yet, FG moderators were stunned by how many times the participants discovered, during the discussion, that other HECs were working or had worked on similar issues, without the other committees knowing. To favor networking, the creation of a website is considered essential:

> In my opinion, if a committee organizes an interesting event, it should share with the other committees […] The same goes for documents and educational materials. We need a website. (*physician*)

> Communication among committees is patchy. That's why we have asked many times the Region to support us in the creation of a website. Alas, without success […] Committee coordination is certainly among the main goals of the Regional Bioethics Committee, but so far it has not been done properly (only via email or phone calls), for lack of sufficient means and personnel. (*law expert*)

A second crucial need mentioned by virtually everyone is the committee members' bioethics education:

> If I have to critically analyse our experience, I must admit things have started working better when some of us begun a process of formal education on clinical bioethics issues. […] It would be great if we could have educational events for the whole regional network. (*physician*)

> HEC members must have a basic bioethics education. […] Indeed, in the ethics analysis of clinical cases it is essential to make reference to a larger framework, to general principles, otherwise there is the risk of simply expressing personal gut feelings, without being able to properly justify the committee opinion. (*law expert*)

A third need mentioned by some FG participants is innovation. For instance, on the face of the difficulties that many committees have experienced in getting cases to discuss, some suggested the opportunity of trying out new tools or methods:

> I believe we need to understand how we could provide ethics consultation more efficiently. Maybe we could introduce the figure of the ethics consultant, next to the committee. Let me use a soccer metaphor: we need someone scoring the goal, finalizing the work of the committee. (*theology expert*)

Finally, a common cry emerged during the FGs has to do with the urgent need for basic material preconditions such as dedicated time, dedicated personnel and some money (for buying books, organizing educational events, granting a fee to external HEC members, etc.):

> It is imperative that the committee members have dedicated time. If healthcare professionals are completely absorbed by their job, they cannot devote any time and energy to ethics. […] There is the need to think, and rethink, about the problems at stake in order to develop reasoned opinions and to elaborate emotions. We need reflection. It is a common experience, I think, that having time for reflecting together is one of the most powerful resources of a committee. (*general practitioner*)

> I want to say that the energy and the passion of our committee chair is the key factor for the

> functioning of the HEC. Therefore, I agree that we need to grant those in the committees, especially chairs, with the time to properly work on bioethics issues. (*social worker*)

4. Discussion

In order to make sense of the first recurrent theme (the dichotomy between the perceived importance of the HEC by its members and the scepticism or indifference among many healthcare professionals), we think it is useful to analyse these two elements separately.

As to the reasons why the participation in the HEC has been an enriching experience for so many committee members, we suggest there are at least three. Firstly, participation in the HEC teaches the art of argumentation: it gives refined concepts to clearly express previously confused moral intuitions and it provides good reasons to justify the final opinion. Secondly, the experience within the HEC furthers moral sensitivity, i.e. the capacity to perceive moral issues in the daily practice and to grasp the moral implications of healthcare choices. Thirdly, participation in the HEC has a "therapeutic" or "healing" function [23], since it helps to overcome the loneliness of the healthcare professionals and to jointly elaborate moral uncertainty.

On the other hand, very often ethics committees are ignored or little valued, especially by physicians. How is it possible to explain this phenomenon? The first cause of such underestimation has to do, we believe, with Italian academic medical education: ethics has little place, and consequently little legitimization, in the curriculum. Generally, doctors are excellently trained from the scientific point of view, but almost not educated in bioethics. The implicit message is the following: ethics is not an essential component of the medical profession. Moreover, physicians' scepticism towards HECs and their lack of interest in bioethics seem an effect of the cultural situation of Italian healthcare, where doctors are conceived as the "disease experts", while nurses are more attentive to the personal and psychological dimensions of care. In addition, physicians are often not used to working in an interdisciplinary manner, as is required in the bioethics field. Finally, some are persuaded that either moral expertise is impossible [24] or that ethical sensitivity cannot be developed, furthered, refined; therefore, it would be useless to have an educational programme in ethics.

The second main theme we have identified is lack of homogeneity. Indeed, some committees consider themselves, overall, as useful and relevant; others admit they are struggling. Some perform all typical HEC functions, other committees just one. Moreover, a few HECs feel well supported by the management, others not sufficiently. Such noticeable variety among committees of the same network seems to signal a structural weakness of the system: presently, each committee is very much dependent on the bioethics sensitivity of the nominating institution management, on the passion, time and preparation of the chair, on the dedication and involvement of its members. While it is long known that these factors are relevant [25-28], the problematical issue here is that institutional supervision appears to have been uneven and, as a consequence, bioethics services have not

been uniformly guaranteed throughout the region.

The discussion about the future, which was the third main theme in the FGs, signals that the Veneto HECs network is experiencing a crisis of growth, as has happened to other networks at a similar stage of development [29]. There seem to be a mix of high potential and serious weaknesses. The specificity of the Veneto network crisis of growth seems to be the conjunction between the "failure to thrive syndrome" and uneven support. If it is in the hands of existing HECs to proactively improve institutional bioethics, the duty of effectively coordinating the network should be exercised by the nominating institution.

5. Conclusions

The Veneto Region network of HECs is unique in Italy and has few parallels in Europe. Our FG study on the opinions of expert HEC members has shown that, on the one hand, such network is relevant and full of potential; on the other hand, that its Achilles' heel is the uneven institutional support and coordination.

The lessons we can learn are the following.

The institutions who want to create a network of HECs are about to take an important and forward-looking decision. Indeed, establishing such a network has both a symbolic and a practical meaning. Symbolically, it shows that the institution values the idea of communal ethical reflection as an essential part of its own life and activity [30]. Practically, it creates open and stable moral-reflective spaces which are much needed both by healthcare professionals and by patients and their families. In addition, it provides the healthcare setting and the community at large with a powerful tool for fostering initial and continuous bioethics education and sensitization.

Nonetheless, for this enterprise to work, the support and recognition by the nominating institution should be long-term. Only this way a network can get what is needed to grow and thrive: effective coordination; common educational materials and events; appreciation and promotion of its richness and creativity – like in the case of Norway [31]; a document on the core competences for providing healthcare ethics consultation – like in the US [32] and UK [33]. Furthermore, steady coordination may help to reduce differences among committees, and clear official support may help to contrast the widespread scepticism towards healthcare ethics committees, and more generally towards bioethics and shared moral deliberation.

However, HECs are just a piece of the larger jig-saw puzzle of ethics services and, more importantly, of ethics culture. In the long run, for HECs to be truly relevant, there is the need for the whole system to move together in the same direction. Upstream, this requires the serious and systematic introduction of bioethics teaching in the curriculum of all healthcare professionals; downstream, the involvement of the general public in initiatives of bioethics sensitization.

Finally, further empirical research would be needed to better study this and similar HEC networks and to understand in depth both the reasons behind the scepti-

cism towards healthcare ethics committees and the preconditions of the effectiveness of their work.

Competing interests

Two of the four authors have had direct experience within the studied network.

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