CLINICAL ETHICS

Hospital based ethics, current situation in France: between "Espaces" and committees

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Unlike research ethics committees, which were created in 1988, the number of functioning hospital based ethical organisations in France, such as clinical ethics committees, is unknown. The objectives of such structures are diverse. A recent law created regional ethical forums, the objectives of which are education, debate, and research in relation to healthcare ethics. This paper discusses the current situation in France and the possible evolution and conflicts induced by this law. The creation of official healthcare ethics structures raises several issues.

Research ethics apart, there are numerous structures dealing with healthcare ethics and bioethics in France. Recent changes in the law have fostered innovations, with the simultaneous creation in various locations of "Espaces éthiques" (ethics forums) and "Comités d'éthiques hospitaliers" (hospital ethics committees), both sited within hospitals. What are these structures? How do they differ? How is the situation evolving? This paper describes a complex transitory situation at a potentially historic moment of healthcare ethics in France: the creation of government supported regional ethical bodies related to university hospitals. I will provide a short historical perspective of ethics committees in France and then describe and discuss the current state of affairs.

RESEARCH ETHICS AND HEALTHCARE ETHICS SINCE 1988

Local ethics committees have been in existence in large French hospitals for over 20 years. Initially, they were mainly or entirely medical in their composition, and devoted mostly to research ethics.^{1 2} They reviewed research protocols that were submitted by their local peers in a totally unevaluated manner. Their legitimacy and the fact that they did not function on a legal basis raised concerns and criticism. Occasionally, they could help in examining difficult clinical situations and sometimes provided recommendations.

Without any linkage to local structures, the French National Ethics Committee (Comité consultatif national d'éthique (CCNE)) was created in 1983 by president François Mitterand. This advisory body comprises 40 reference individuals nominated directly by the government and produces reports on request. It is not involved in research protocol examination,

nor in casuistry. In 1988 the CCNE published a directive "regarding local ethics committees", and the necessary improvements required in the field of research ethics. In this directive, the CCNE required that all research protocols should be submitted to a committee (as recommended in an earlier proposal relating to human research), and discussed the possible ways in which such bodies should function and how they should be composed, aiming at harmonisation.^{3 4} It accepted that various tasks in addition to the evaluation of research projects were undertaken by the existing committees, such as help in clinical practice, involvement in problems of a general nature, and education. The CCNE directed that these activities should be continued, stating that "Committees will make pronouncements on issues involving research on human beings, will formulate opinions on ethical problems arising out of research, and will contribute to training and public information based on their consideration of these ethical matters". However, a French law regulating research ethics, passed in 1988 shortly after this CCNE directive, created a division by setting up independent regional research ethics committees which were strictly limited to examining research protocols.

As a result, the former hospital ethics committees had either to be disbanded, which occurred to some of them, or to reorient their activities. Several of those committees then organised various types of meetings on topics related to ethics, and an unknown number provided ethical consultations.

Over the past 20 years, local ethics activities within hospitals have not been limited to the few committees remaining from the pre-1988 era. Many initiatives have been carried out, mainly promoted by personal hospital health care providers interested in ethics, and by growing social concerns about ethical issues. What exactly was happening in the hospital setting was not observed prospectively, so those structures and the nature of their activities were not recorded as they appeared, and their functioning was very poorly documented. As was shown later, not all these bodies were named committees, and the ways they work were, and still are, diverse.

In 1995, a structure called "Espace éthique" was created by Emmanuel Hirsch within the Paris public hospital group (Assistance Publique – Hôpitaux de Paris).^{5 6} The Espace éthique approach is based on the recognition of the

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Abbreviation: CCNE, Comité consultatif national
d'éthique

legitimacy of those who are the direct actors in healthcare situations with regard to professional ethics awareness and debate. It postulates that they are the only ones with a good empirical knowledge of what is at stake, and therefore among the most appropriate persons to identify relevant issues. Moreover, it considers them to be responsible moral agents in the exercise of health care. It recognises the need for cultural, educational, and methodological support in this task, and aims to provide it. The Espace éthique's design was innovative as its aims were first to involve stakeholders themselves in research into ethical problems, and second to make high quality education in ethics directly available to professionals in the hospital setting. As such, this organisation is profoundly different from a committee, being composed of identified members of a specialised group which produces ethical reflections or provides ethical advice through consultations. The team of the Espace éthique does not provide decision-making advisory work. Its response to requests for consultations is to analyse with the person making the request the reasons for the request, and then to propose contacts (often judicial) or educational programmes, or invite the person and other relevant stakeholders to participate directly in a research activity designed in partnership with the Espace éthique team and according to the context. Ultimately, no answer is provided to the question that triggered the contact, but the reasons for the professional feeling the need for "ethical help" are explored and the issues clarified.

Two years later, a second Espace éthique was set up in Marseille, by a local team led by a former health minister, Jean-François Mattei, which took the Espace éthique/AP-HP as a model. Other structures followed—calling themselves Espace éthique, though not always functioning in a similar way—and some worked as committees. In contrast, some of the newly set up structures called "committees" by their initiators aimed to provide support for health carers and other stakeholders who themselves provide ethical expertise, thus working as an Espace. Finally, some of these structure have adopted both models: on the one hand they provide support before any consultation request (through education and methodology), while on the other hand they provide various types of advice in relation to practical situations. Thus at present the name of the structure does not relate in any systematic way to its function.

HEALTHCARE ETHICS AS A "LEGAL OBLIGATION"

In March 2002, "hospital ethical reflection" appeared in law for the first time, with the following sentence: "[Hospitals should] undertake, within their structure, to reflect on ethical issues related to patient's reception and medical care".⁷ This first acknowledgement of the importance of hospital based ethics in legislation might have encouraged some hospitals to undertake initiatives, but it was never followed up with the necessary specifications describing in concrete terms what is prescribed in the legislation. Such ethical reflections are not carried out in all hospitals, and the persons who set up ethical bodies often do so without being aware of the existence of this article in the law.

The first survey on a national scale on ethical activities in hospitals was carried out in 2003 by the Espace éthique/AP-HP.⁸ This survey—though not exhaustive (because it did not cover all hospitals, and because not all the structures contacted responded)—showed that at least 115 local organisations dedicated to health care ethics were functioning by this date. One third of them had been in existence for under five years, suggesting a high rate of creation. Their activities were diverse, covering philosophical and research aspects of ethics, education, the organisation of meetings, and advisory work. Advisory work involved either making

general recommendations or providing specific help for healthcare professionals facing a difficult situation.

In April 2004, the CCNE published an opinion regarding ethics education for healthcare professionals.⁹ Among other recommendations, the CCNE encouraged the implementation of regional resource structures based on the Espace éthique standard, as follows: "The regional espaces éthique (ethics forums), which are the focus of education and research, are distinctive in that they are open not only to health carers but also to jurists, philosophers, psychologists, scientists, representatives of associations, and many others. They are also forums for exchanging experience and knowledge. [...] Health carers can assemble according to preference, competence, concern (pain, management of the disabled, medically assisted reproduction, etc) in discussion groups [...]. The objective would not be to hand down directives or recommendations in urgent clinical situations or when a medical decision needs to be taken immediately. On the contrary, the ethics forums would fill the need to gain a perspective distant from the emotional situation generated by the heat of the action, and for rethinking the meaning and objectives of a particular activity. As a meeting point, regional ethics forums provide the possibility for physicians and jurists to exchange views on health issues elsewhere than on the scene of disputes, to which their relationship seems to have been confined in recent years. On a general level, these regional centres represent an opportunity to escape the barriers erected between disciplines that have long been the bane of the French university system." In another paragraph, this CCNE report recognises on a separate level the existence of local hospital ethics committees which would aim to provide ethical consultation or advice. It differentiates them from the regional ethical forums which it encourages. The paragraph explaining the purpose of local ethics committees reads: "These structures for ethical assistance in decision-making are [...] totally unlike the ethical forums (espaces éthique), as their objective is to propose a response to a practical question." However, the CCNE report failed to recommend whether the many local committees already in existence that carry out both decision-making activities and research and educational activities should or should not continue to carry on these activities.

The most recent legal step occurred in August 2004, when the law was strengthened by another article which stipulated: "Espaces de réflexion éthique are created at the regional or interregional echelons; they work in connection with university hospitals and they are sites of education, documentation, interdisciplinary meetings, and discussions on ethical issues in the field of health. They also are regional and interregional observatories with regard to healthcare practices. They participate in the organisation of public debate so as to foster information and consultation on bioethics issues with and for citizens".¹⁰ Thus the law now embraces the model of Espace according to the opinion of the CCNE. This legislation does not mention hospital ethics committees.

This law has not yet come into force, as another legislative step is necessary—a specification decree must be published officially, containing information about how to proceed in practical terms. Among other technical difficulties, the wording "work in connection with university hospital" tends to make the situation rather complex for those in charge of writing the application decree which will trigger the practical enforcement of this new law: strictly speaking, those Espaces de réflexion éthiques ought not to be *hospital based*, but *connected to* university hospitals. Besides, during the past 18 months, since the law was passed, various kinds of "regional Espaces éthiques" have emerged spontaneously (sometimes several for one region, at least for Brittany, Normandy, and

Provence-Alpes-Côte d'Azur), and many hospital ethics structures continue to participate as actively as possible in public debates, often wondering how they should evolve. For all of these, the facilities and human resources are hospital based, and all still work with virtually no specific funding. In September 2005, the second national meeting of the Espace éthique gathered contact persons identified either from the national directory established in 2003 or by personal contacts that took place in Marseille. Among various participants, 17 ethical bodies were represented, of which eight described themselves as "regional". Discussions during this meeting showed that the "regional" structures differed from the others in many ways. The term "regional" is still self assessed, until further official specifications are provided.

Neither the way existing hospital based structures will be involved or will contribute to the future Espaces de réflexion éthique, nor the funding sources, nor the regional organisation, nor the profile of the organising members is currently known. At the time of writing, an expert working group on these aspects was still being set up at the French health ministry and had not had its first meeting.

AFTER 2005: RESHAPING ETHICS STRUCTURES IN HOSPITALS?

From a general perspective, the current functional description contrasting the so-called Espace éthique and the ethics committee frameworks raises at least two problems. First, as explained above, many structures adopt both models. Second, the question of the definition of an advisory activity arises. For instance, members of non-advisory structures can enter the decision-making processes at various entry points, officially or non-officially, by individual or collective interactions, and can have a strong though invisible influence. In contrast, advice from an advisory body may not be followed if the persons requesting the intervention find the advice morally inappropriate. Such paradoxes always involve a grey zone about the actual function of an ethical organisation working "indoors" in the health care system, whatever this organisation's identity, because it has identified members who are seen as special interlocutors with respect to ethical issues.

The nature of the links of future Espaces de réflexion éthique with hospitals (whether or not those structures have a physical existence separate from the hospitals) remains to be clarified. I would find it somewhat paradoxical to separate geographically the future Espace de réflexion éthique from the hospitals. I believe that physical proximity is essential: hospital stakeholders must be the ones to enter the Espace de réflexion éthique, and everything should be done to facilitate this. This calls for a reflection on the nature of what comprises a "good distance" in the relationship between ethical bodies and healthcare professionals. Such debate should lead to an understanding of good "ethical practices", and to the elucidation of prerequisites such as the legitimacy of ethical organisations. Such essential work has not been done as yet in France. The so called "Espace éthique approach" refutes any kind of participation in casuistic decision-making processes because there is a risk that decisions will favour medical expertise, and there is a strong need for ethical advisory bodies to be seen to be independent from these pressures. The demand for ethical expertise is growing dramatically at present (often linked to the request for legal back-up). In this context, the official recognition of ethical structures will probably give them a new image, and may create an increase in requests for advice. This could lead to tensions reflecting a misunderstanding of their responsibilities as listed in the 2004 law: that is, they should remain purely supportive with no intervention in particular decision-making activities.

Two possibilities are thus open in the future: either the regional structures will stick to the supportive approach, or

pressures will make them take on new functions by getting them involved as direct actors in practical situations.

In the first scenario, regional Espaces éthiques will have to deal with a contradiction in their relationship with local structures that provide ethical consultations. Espaces éthique would consider requests for consultations as indicators of a need for education and for the provision of tools that would help preserve professional autonomy, while local ethical groups that provide consultations would consider such requests as the justification of their function. Meanwhile, those local organisations which, as well as playing an educational role, also provide documentation or professional participation in ethics research would naturally be relevant interlocutors and partners for the regional Espaces éthique.

If the second hypothesis occurs, then a totally new situation would exist—the possible and official direct intervention of outside stakeholders in decision-making processes in hospitals. This was not required by the law, but for many, the existence of official "ethical structures" half way between the rather unknown local ethical committees and the national ethics committee could fulfil the need for regional Espaces éthiques. There is a recent illustrative example of this kind of confusion. During the process of work on the specification decree for a recent law on a patient's rights at the end of life, an official at the ministry proposed the direct participation or supervision by a (future) regional Espace éthique representative in local discussions leading to decisions about withholding or withdrawing treatment.¹¹ This proposition was rapidly discarded, but it shows that even well informed official stakeholders may participate in the creation of new demands.

Beyond this, one of the most important issues today is the identification of the sources and circumstances of ethical reflection. What makes this question central for future Espaces de réflexion éthique is that they should work as supportive platforms and as knots of networks more than as consultative bodies. Thus plural partnerships, communication, organisation, reception, and educational means should be placed at the first level in this debate. The "espaces de réflexion" (room—and time—for reflection/space for reflection) should be above all the facilitating frame, and its future organisers' skills may not have to be only in the academic field of ethics. Those discussions should not disregard other sources of ethical reflection by organisations whose purpose is not initially to facilitate such reflection, but they are among the most relevant participants in such work. They include scientific societies and patient's representative associations. The scientific societies and medical organisations are involved in an increasing amount of work in the ethics of their fields at a national level. A well known example is the work of the SRLF (Société de réanimation de langue française)—the national scientific organisation of intensivists—about end of life issues in intensive care units. As for the patient's representative organisations, some of these are now strongly involved in ethical issues, in association with health care professionals, and have produced very relevant reports. A good example, among others, of such initiatives is one by the ARS (Association pour la recherche sur la sclérose latérale amyotrophique et les maladies du motoneurone), working in the field of amyotrophic lateral sclerosis. The identification of the potential sources of ethical reflection, and an inventory of work currently being done by bodies such as scientific societies and patient's representative associations is currently being undertaken in France as a research project.

CONCLUSIONS

The best way to describe the situation in France today with respect to hospital based ethics (research ethics committees

are not considered here) is probably “evolution towards recognition.” Hospital based structures are numerous and diverse. Willingness is often the basis of their activities, and their composition and methods are very varied. Some of those structures provide consultation and participate in the decision-making processes at some stage when they are requested to do so, while others are reluctant to be involved. The incorporation in law of regional structures dealing with ethical reflections raises issues about the evolution of such structures: some of them may become obsolete, while others may evolve with new regional responsibilities. This recent addition in the public health act is revolutionary—it creates officially new ethical bodies supported by public funds.

The issue of turning healthcare ethics into a profession, or several professions, clearly needs to be raised in a country where so far the word “ethicist” is very seldom used and has not been defined. The ideal in my view would be a strict understanding of the new law in its application—that is, placing the activities of the regional Espaces éthique in a supportive role, with a possible direct participation in ethical debates by their future members, while avoiding classical ethics consultations. The role and skills of their future members should be in the fields of organisation and observation. They should not pretend embody the essence of ethical decision-making, which primarily belongs to those who are directly involved.

In relation to ethics consultation activities, these require close observation and evaluation of their functions, but systematic work may be difficult as there has been no satisfactory record of the structures involved and of their activities in France up to now, unlike in several other European countries. However, such an evaluation calls for more reflection on the decision-making processes within

hospitals, carried out by working teams. Failure to understanding this may create situations where such a service only covers matters that could have been resolved if they had been thoroughly identified.^{12–16}

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