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Embedding clinical ethics in a health care system: The experience of the UK clinical ethics network

_ Original article

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Abstract _ German and French abstracts see p. 43 & 44

The development of clinical ethics committees in European countries has been increasing in momentum over the past ten years. The health care systems and regulatory frameworks in which these committees are developing vary widely shaping their specific structure and procedural role but the committees share many similar challenges. These include isolation within their institution, ambiguities in standard setting, and engaging with the wider health care system. In the UK a national Network of clinical ethics committees was established in 2001 in part to address some of these challenges. The Network provides opportunities for clinical ethics committees to share experience and to access educational and other resource materials, and has developed a critical mass which can engage with policy making organisations to raise the profile of clinical ethics within health care. The Network has been successful in achieving some of its aims but less so in achieving others. The experience of the UK Clinical Ethics Network can be helpful to those seeking to develop the field of clinical ethics, and specifically support developing clinical ethics committees in other countries.

Key words: Clinical ethics; network; committees; standards

Clinical ethics can be viewed from two different perspectives. On one viewing it is seen as a subject area of the theoretical field of bioethics, bringing the tools of ethical theory to bear on dilemmas situated in the context of clinical practice. On the second view clinical ethics is seen as a subject area within the field of health care. On this view the practice of ethics in the clinical setting would form the cornerstone of the discipline, as with other clinical disciplines, for example cardiology. Each clinical discipline has a clinical or service delivery component which is its central focus, but it also has, indeed requires, a theoretical and research component on which the practitioner must draw in order to practice effectively. Similarly the focus of clinical ethics is on the delivery of ethically informed and appropriate care which also requires a well developed theoretical and research component. Situating clinical ethics within a primarily clinical rather than theoretical field has two key consequences. It emphasises the importance of the experience of ethics in clinical practice as an active rather than passive component of the development of moral theory in relation to medicine. It also generates a requirement for clinicians and managers within health care to recognise the importance of and take steps to embed the practice of clinical ethics into the day to day provision of health care.

Over the past 30 years we have seen a gradual increase in the number of clinical ethics committees and ethics consultants in health care institutions across the world (1) (2) (3) (4) (5) (6) This development of a service delivery component of clinical ethics has often been sporadic and uncoordinated resulting in variable standards of practice (7) (8) questions of legitimacy (9) and low impact on the overall delivery of health care (10) A major problem for many clinical ethics committees is isolation, both within the institution in which they sit and within the wider context of clinical ethics support in their particular health care system (11) (6). Without appropriate mechanisms to share experience, learn from others more expert in the field and contribute to the development of research that will then inform future practice, clinical ethics is unlikely to become robust enough to be recognised as a distinct and important area of health care practice and CECs risk becoming disillusioned and ineffective. In North America the number of CECs and ethics consultants is probably great enough to create a critical mass that can influence the development of clinical ethics within health care but this is not the case elsewhere, including most European countries. In this paper I describe one approach (the UK Clinical Ethics Network) to development of such a critical mass with, at least initially, a handful of committees and I consider whether this approach can be a useful way of embedding clinical ethics as a core subject area in the field of health care.

The UK clinical ethics network

In 2000 the Ethox Centre conducted a survey of the provision of clinical ethics support in all UK National Health Service (NHS) Trusts (12). One key finding of the study was that the few clinical ethics committees that were in existence at that time in the UK had no knowledge of any other CECs within their region, or indeed nationally. Each committee was working in isolation, developing its own terms of reference and operational procedures, and negotiating its position within the organisation with varying degrees of success. All of these initial committees were loosely based on the North American model as described in the literature. The Oxford committee was established under the guidance of a clinical ethicist with wide experience of the Canadian model of CECs but most committees had no specific academic ethics input in their early stages. Clearly if CECs were to have any impact on the development of clinical ethics within UK health care they would require further support. In 2001 at a meeting of CEC Chairs in Oxford it was agreed that a Network would be an effective method of co-ordinating support for CECs, sharing good practice, developing standards, and raising awareness of clinical ethics within the health system as a whole. The aspiration was that through a Network it would be possible for CECs to have a combined effect on the development of clinical ethics within UK health care that was significantly greater than that which they could achieve in isolation in one hospital. In the six years since its establishment the Network has had variable success in achieving its initial aims, as described below.

Supporting the development of CECs

Since 2001 the number of CECs in the UK has risen from 20 to 78 (it is possible that there are others not known to the network). Many of these committees have approached the Network for guidance and information during their initial development and often prior to formally establishing a committee. The Network has been able to offer support in a number of ways. The network website provides a range of information for fledgling ethics committees including contact details for other committees, links to relevant national policies and guidelines, brief introductions to the key issues that are likely to come to a CEC (consent, confidentiality, end of life decision-making etc) and a practical guide to clinical ethics support (www.ethics-network.org.uk). The website and other resource materials have a significant academic input from the Ethox Centre through its clinical ethics support project, but the input from established CECs is crucial in ensuring that the material developed is relevant to the experience of providing clinical ethics support within the UK health care system. Thus the practical guide has a series of appendices written by individual committees describing their experi-

ence of different aspects of setting up and running an effective CEC. Similarly the educational resources are piloted with CECs and the website editorial board which reviews the content of the website includes members of CECs in addition to academic ethicists, clinicians and lawyers.

Sharing good practice and developing standards

The original CECs identified in 2000 strongly emphasised the importance of being able to learn from other committees and share examples of their work, particularly around development of policy and guidelines for their institution. They expressed a desire to avoid «reinventing the wheel» where possible. Committees are encouraged to share any significant policies or guidelines that they develop with other committees and this has occurred in some instances. The website is one mechanism for this as is the Network «round robin» (see below). This has however proven difficult to implement successfully for a variety of reasons. For a CEC to permit publication of what is in effect a hospital policy on a publicly accessible website or even to distribute it within a Network of other committees requires appropriate permission from the hospital. Also to be proactive in seeking policies from committees, maintaining some form of database and updating it regularly is a major administrative burden which the Network is not in a position to undertake. A more successful method of sharing experience has been the Network round robin. This is an e-mail discussion which can be initiated by any CEC who either wishes to know whether other committees have considered a particular issue or would like to share their experience of developing a policy in a specific area. The e-mail responses from other committees are collated with a commentary which is then circulated to all committees within the Network. Examples of round robin topics have included withholding life sustaining treatment, advance directives, HIV testing of an unconscious patient, patient restraint, neonatal circumcision, and the position of an ethics committee in the hospital management structure. A recent criticism of the Network has focussed on its failure to take a position on the competency of CECs to perform the functions that they say they are carrying out, specifically their competence to advice on individual cases, and the development of an educational programme for CEC members (8). The need for an agreed statement of core competencies and a minimal set of training requirements for CECs was highlighted in the recommendations of the Report of the Royal College of Physicians working party on clinical ethics (13). In response to this the Network has developed a position statement on core competencies which has been submitted for publication.

Raising awareness of clinical ethics

One of the stated aims of the Network is to promote the development of ethics support in clinical practice in the UK. This aim is broader than simply supporting the development of individual committees and recognises the need to increase awareness of the concept of clinical ethics and clinical ethics support at all levels within the wider health care system. Clinical ethics committees have developed in the UK, and in many other countries, because of an expressed need by health professionals for support and advice in dealing with the ethical difficulties they are encountering in their day to day practice. The question of whether CECs are the most appropriate response to this need has been a subject of debate but this does not diminish the imperative for explicitly recognising the ethical difficulties encountered in clinical practice and the lack of mechanisms to support health professionals in resolving them. The UK Clinical Ethics Network has worked to increase this recognition within national organisations and professional bodies to establish clinical ethics as a key component of good clinical practice. This has included responding to national consultation exercises on ethical issues by the Department of Health and the British Medical Association; working with the ethics interest groups of professional organisations to run conference sessions; and working with the General Medical Council in relation to their professional guidance to doctors. In 2005 the Royal College of Physicians published the results of a working party enquiry into clinical ethics which concluded that *«the provision of timely, comprehensive ethics support should no longer be left to chance or be dependent on the enthusiasm of individuals»* and that *«Healthcare institutions should review their existing arrangements for providing advice and education, and developing and implementing guidelines on the recognition and handling of ethical uncertainties and dilemmas in clinical practice (13).»* This report, by a highly influential Professional Organisation, was informed by contributions from both the Network and individual CECs, and indeed it was partly the presence of increasing number of CECs within the health service that provided the initial stimulus for the working party to be established. More recently the Nuffield Council on Bioethics has published a report on the ethical issues in critical care decisions in foetal and neonatal medicine which recommended that *«...NHS trusts should explore ways to ensure that all neonatal intensive care units have rapid access to a clinical ethics committee, available to families and staff (14).»* Thus, by engaging with national and government organisations the Network has contributed significantly to the increasing recognition of clinical ethics as an important component of the delivery of health care in the UK.

How generalisable is the experience of the UK network to other countries?

It is not clear how many national clinical ethics networks exist. There has been a history of State based Networks in the US and in Canada there are at least two very active Networks, one co-ordinated by the Joint Centre for Bioethics in Toronto (<http://www.utoronto.ca/jcb/home/main.htm>) and one in Alberta (<http://www.phen.ab.ca/>). In Europe, Norway has a national network (http://www.med.uio.no/iasam/sme/kek/kek_engelsk/english.html) and anecdotal evidence suggests that they may be developing in other countries. Many of the North American Networks have been established either by an academic centre or by a regional health organisation (15) (16) (Pinkus). In the UK by contrast whereas the initial catalyst was provided by the Ethox academic centre, the main driver for the development and maintenance of the Network has come from the individual committees that make up the network. For example the national conference is organised and hosted by an individual CEC and not by Ethox.

There are advantages and disadvantages to this bottom up approach. The lack of any requirement or regulatory framework for CECs from national or regional health management in the UK means that there are very few resources available to support individual committees or the Network. This restricts what can be achieved in terms of supporting committees and developing effective training for members with concomitant risks for the quality of service provided by CECs. It also means that there is no formal evaluation of their work. However the CECs that have developed and are part of the Network have a clear enthusiasm and commitment to the importance of clinical ethics within health care generally and within their own institution in particular. This may not always be the case for CECs in a system that has a legal or regulatory requirement for health care institutions to have a CEC. In the latter context there is a risk that having a CEC will become a paper exercise for the institution rather than a concrete illustration of the institution's commitment to embedding ethical considerations into day to day practice. This appears to have been a problem in some European countries where a legal requirement for institutional ethics committees has resulted in many committees focussing on research ethics rather than ethical reflection in clinical practice. Steinkamp et al have suggested that there should be central regulation of CECs but that the regulation should be weak rather than strong to facilitate biomedical citizenship and ethical reflection (17).

The lack of a strong regulatory framework for CECs in the UK has helped the development of the Network because there was a clearly identified need on the part of individual CECs to seek shared experience and expertise to inform their development rather than look to official guidelines or policies. A second factor facilitating the development of a national network is the organisational context of the health service in the UK. Although there have been many changes to the national health service (NHS) in recent years it is still fundamentally a national, publicly funded service and all health

care institutions within the service share a common organisational structure and set of core values. Thus individual clinical ethics committees will have a common understanding and experience of the context within which other members of the Network are working. Some private hospitals in the UK also have a CEC and these are members of the Network but they are few in number and in practice contribute less to the Network than the NHS based committees. In countries with diverse models of health care provision development of a national network might be more challenging with respect to identifying areas of common experience. This shared organisational context also facilitates the Network's ability to enter into dialogue with national organisations such as the General Medical Council and the British Medical Association as well as the Department of Health. There are 167 Acute Trusts (hospital organisations that deliver acute medical care) and 43% of these have a CEC that is a member of the Network. This represents a substantial resource which professional organisations and policy makers can engage with.

Opportunities and threats to future development of the network

As an established national network with an increasing membership as more NHS Trusts establish a CEC there is a great opportunity for the UK Clinical Ethics Network to influence the development of clinical ethics in the UK and to embed it in the health care system. Key areas for the Network to become involved in are development of standards for CECs, audit and evaluation of clinical ethics support, education of CEC members and providing a link between health care (at the coal face) and policy makers. The Network has the potential to play a key role as a link between the health professionals and managers (on the ground) and policy makers to both inform policy making on ethical issues and to translate policy into practice locally. An example of the latter has been a recent project between the Network and the Ethox Centre funded by the Department of Health to raise awareness among health professionals of the legislation on treatment of persons who lack capacity (18). Regional workshops for CECs have provided education and discussion on the ethical principles underlying the legislation as well as key components of the code of practice. These workshops, supported by web based resources on the Network website have enabled CECs to advise and educate health professionals within their organisation on the implications of the Act for ethical decision-making in their day to day practice. However if the Network is to move forward on these areas and respond to the challenges of its critics it will require significant resources. Experience in North America shows that access to adequate resources have influenced their success (15). A number of regional ethics networks developed in the 1990s but many disappeared due to lack of resources. Those networks that have been well resourced have been able to demonstrate significant impact at a regional level on both clinical practice and health care policy. The UK Network has recently become a registered Charity in order to facilitate opportunities for

funding of its work. However stable funding is only likely to occur when clinical ethics is recognised more widely within health care organisations regionally and nationally. We hope that the Network can continue its profile raising work in this area long enough for this recognition to occur.

Conclusion

The development of clinical ethics as specific subject area within health care incorporating clinical practice, research and theory will create an environment in which ethical awareness and ethical decision making are explicitly recognised and embedded in day to day practice. Clinical ethics committees and ethics consultants can be seen as the formal aspect of its service delivery component (other informal mechanisms of ethics support are also important). CECs can influence the integration of clinical ethics within their individual institutions but are less effective at influencing wider health care systems particularly at a national level. A national Network of CECs has several benefits for developing clinical ethics within a health care system. It can assist the development of individual committees, contribute to standard setting and education of committee members, and act as link between practitioners and policy makers. The UK Network has been successful in some of these areas but its experience highlights that adequate resources are required for Networks to fully realise their potential contribution to the embedding of clinical ethics securely in a health care system.

Conflict of interest: Dr Slowther is Director of the academic and administrative support project for the UK Clinical Ethics Network. Her work in this area is funded by the Ethox Foundation.

Zusammenfassung

Die Einbindung der klinischen Ethik in ein Gesundheitssystem: Die Erfahrungen des Netzwerks klinischer Ethik in Grossbritannien

Die Einführung von klinischen Ethikkommissionen in verschiedenen europäischen Ländern hat in den letzten zehn Jahren sprunghaft zugenommen. Diese neuen Kommissionen sehen sich alle mit ähnlichen Schwierigkeiten konfrontiert, obwohl sich die Gesundheitssysteme und staatlichen Rahmenbedingungen, in denen sie sich zu entwickeln haben, teilweise erheblich unterscheiden. Diese Schwierigkeiten umfassen die Isolation innerhalb ihrer eigenen Institution, die Unsicherheiten im Festsetzen von Normen und ihre Rolle im Gesundheitssystem. In Grossbritannien wurde ein nationales Netzwerk von klinischen Ethikkommissionen gebildet, um zumindest einigen dieser Herausforderungen angemessen begegnen zu können. Dieses Netzwerk ermöglicht den Kommissionen den Austausch von Erfahrungen, verschafft ihnen Zugang zu Bildungs- und anderen Materialien und hat nun eine kritische Grösse erreicht, die es erlaubt,

sich mit politisch aktiven Organisationen zu verbinden, um die klinische Ethik im Gesundheitswesen sichtbarer zu machen. Einige ihrer Ziele konnte das Netzwerk bereits erreichen, andere noch nicht. Die Erfahrungen dieses Netzwerks der klinischen Ethikkommissionen in Grossbritannien können zum einen hilfreich für die Weiterentwicklung der klinischen Ethik sein und zum anderen den Aufbau von klinischen Ethikkommissionen in anderen Ländern unterstützen.

Résumé

Intégrer l'éthique clinique dans un système de santé: l'expérience du Réseau d'Éthique Clinique de Grande Bretagne

Le développement des comités d'éthique clinique a augmenté en Europe dans les dix dernières années. Les systèmes de santé et les cadre réglementaire dans lesquels se développent ces comités variant largement, influençant ainsi leurs structures spécifiques et le rôle procédural, mais les comités partagent malgré cela de nombreux défis similaires. Parmi eux, l'isolement dans leurs institutions, l'ambiguïté de leurs standards, et la difficulté à s'intégrer dans le système de santé au sens large. En Grande Bretagne, un Réseau national de comités d'éthique clinique a été établi en 2001, en partie pour faire face à ces défis. Le Réseau fourni l'occasion aux comités d'éthique clinique de partager leur expérience et d'accéder à du matériel de formation ainsi qu'à d'autres ressources. Il a développé une masse critique lui permettant d'aborder les instances régulatrices et décisionnelles sur les politiques de santé, pour améliorer la visibilité des comités d'éthique clinique dans les soins de santé. Les succès du Réseau ont été bons dans certains domaines, moins dans d'autres. L'expérience du Réseau national britannique d'éthique clinique peut être utile pour le développement de l'éthique clinique, et plus spécifiquement au développement de comités d'éthique clinique dans d'autres pays.

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