

Debate

## Clinical ethics revisited

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### Abstract

A decade ago, we reviewed the field of clinical ethics; assessed its progress in research, education, and ethics committees and consultation; and made predictions about the future of the field. In this article, we revisit clinical ethics to examine our earlier observations, highlight key developments, and discuss remaining challenges for clinical ethics, including the need to develop a global perspective on clinical ethics problems.

### Introduction

A decade ago, we reviewed the field of clinical medical ethics in a series of articles [1, 2, 3, 4, 5]. We said that the goal of clinical ethics was to improve the quality of patient care by identifying, analysing, and attempting to resolve the ethical problems that arise in practice. We assessed research, teaching, ethics committees and consultations, and made predictions about the future of the field. In the original articles, we wrote:

"When we review the field of clinical ethics a decade from now, we hope that the focus will have shifted from ethics courses, committees and consultants to an understanding on the part of most physicians and medical students that ethics is an inherent and inseparable part of good clinical medicine. We hope that clinical ethics will have achieved its rightful place at the interstices of relations between patients who are sick and physicians who profess to be able to heal or comfort them."

Clinical ethics has made progress towards this vision in the last ten years. In this article, we review our observations in the earlier series, highlight key developments during the past decade, and discuss remaining challeng-

es for the field. We will use our original format of dividing clinical ethics into research, teaching, committees and consultation activities, and revisit our predictions for the future - now the present. This article represents the opinions of three physicians who have been active in the field of clinical ethics for a number of years. We hope it stimulates the kind of commentary and debate that our earlier ones did. Finally, although we have mentioned the work of numerous colleagues, we will undoubtedly have overlooked the work of others and hope they will be highlighted in responses to this article.

### Research in clinical ethics

#### *Our earlier observations*

Ten years ago we emphasised the importance of developing a research base for clinical ethics. We argued that research in clinical ethics tended to be defined by the clinical area that it focussed on - for instance, end-of-life care, consent, priority setting, or women's health.

We developed a taxonomy for clinical ethics research, based on method rather than clinical area. This divided research in terms of whether it used theoretical or empirical methods, as shown in Table 1.

**Table 1: Methods of clinical ethics research**

Theoretical	
→	<i>Philosophy</i> (e.g., How should decisions on setting priorities be made legitimate and fair?)
→	<i>Theology</i> (e.g., What Catholic values should guide decisions on setting priorities in Catholic hospitals?)
→	<i>Law</i> (e.g., What practices in setting priorities in a regional health authority might constitute discrimination?)
→	<i>Policy</i> (e.g., What policy should governments follow in funding new technologies in medicine?)
Empirical	
→	<i>Social sciences</i> (e.g., How do regional health authorities in developing countries make decisions on setting priorities?)
→	<i>Decision analysis</i> (e.g., How do you trade-off considerations of equity and efficiency in decisions on setting priorities?)
→	<i>Clinical epidemiology</i> (e.g., What are the criteria used to allocate liver transplants?)
→	<i>Health services research</i> (e.g., How does the delivery of cardiac surgery vary by patient gender or ethnicity?)

Finally, we said that theoretical and empirical research were synergistic. Their combination offered research potential that neither could fulfil alone.

#### Key developments

In the past 10 years, the research base of clinical ethics has strengthened appreciably. The number of new articles in MEDLINE with 'ethics' as a keyword increased in the early 1990s, continuing the trend of the preceding 20 years. In 1993, this number reached a plateau of over 3000 new articles a year.

However, the main research opportunities have not come under the broad heading of clinical ethics, but instead through specific programmes such as the human genome project and the end-of-life movement. The US human genome project devoted 2% of its budget to ethical, legal, and social issues. Meanwhile, the end-of-life movement, with funding from organisations such as the Soros Open Society Institute, the Robert Wood Johnson Foundation, and the National Institutes of Health, helped form the largest single ethics research project of the past decade - the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) study [6].

In the USA, the National Institutes of Health created the Center for Clinical Bioethics under the leadership of Ezekiel Emanuel. The European Community has dedicated funding to ethics projects among member nations.

In addition, the Canadian Institutes for Health Research created a peer review panel for health ethics, law, and humanities that will review grants for the first time in the fall of 2000.

Within empirical research (both in ethics and more generally), there is growing recognition that quantitative methods alone are inadequate. Since many of the phenomena examined by ethics researchers are deeply entwined into the fabric of professions, organizations, and human lives, qualitative methods have begun to play an important role. For example, James Tulsky performed observational research on how physicians discuss do-not-resuscitate orders and advance care planning [7]. The role for qualitative methods is both increasing and broadening to include not only content analysis but also grounded theory, ethnography, and case study designs.

#### Remaining challenges

Most national funding agencies directly fund only a handful of operating grants and career awards for research into ethical issues. Instead, most funding has come indirectly, via the programmes described above. Therefore, the challenge remains for research into ethical issues to become a mainstream concern for funding agencies around the world.

Although almost every major medical and scientific journal now publishes ethics articles, there is more commentary than original research. Peer review of ethics research is of variable quality, although there is no evidence that this problem is worse for ethics than for other types of research.

There are now more than 10 ethics specialty journals. Although these are a welcome locus for publication, their impact factors do not rival those of major medical and science journals - or even some specialty journals - and therefore may not be useful for promotion and career awards for clinical ethics scholars. They are also not read by precisely the sort of front line health care workers ethics authors might want to influence.

There is also often a long time lag between the completion of an ethics research project and its publication, although there is no evidence that this is worse for ethics than other types of health research. This publishing environment needs to change, and with the advent of e-publishing, no doubt it will. The challenge for clinical ethics scholars is to ensure that ethics research takes full advantage of the new e-publishing environment.

Interdisciplinary research might be another means of increasing the visibility and validity of ethics research, something that our earlier articles failed to emphasise

sufficiently. Rosenfield provided the following definitions of interdisciplinary research [8]:

- **Multidisciplinary:** researchers work in parallel or sequentially from disciplinary-specific base to address a common problem
- **Interdisciplinary:** Researchers work jointly but still from disciplinary-specific base to address a common problem
- **Transdisciplinary:** Researchers work jointly using a shared conceptual framework drawing together disciplinary-specific theories, concepts, and approaches to address a common problem

Sadly, there are still too few examples of interdisciplinary ethics research.

There is also a need for inter-professional ethics research, for instance between nursing, social work, pastoral counselling, and other professions. Inter-professional research enriches our grasp of the moral complexities of different professional views. We welcome efforts such as the Tavistock Principles, which attempt to accommodate various professions and develop a shared ethic [9].

Further strengthening of the research base will require strengthening of the capacity to perform research and networking between clinical ethics scholars. We hope that universities, research funding agencies, and journals will increasingly recognise the value of clinical ethics scholarships during the next decade. We also hope that international networks will develop so that learning can be shared across national borders. Such networks, with international research conferences, have begun to form in areas such as end-of-life care, priority setting, and women's health.

## Teaching clinical ethics

### ***Our earlier observations***

Ten years ago we made the following observations about teaching clinical ethics to medical students and clinicians:

- The principal goal of teaching was to improve the quality of patient care
- Teaching should focus on cognitive skills, behavioural skills, and character development
- Teaching should be integrated into all stages of a physician's education, including medical school, residency, and continuing education

- Practising clinicians with formal ethics education brought advantages to teaching, but philosopher bioethicists also had much to contribute

- One of the most persistent and difficult questions was whether teaching clinical ethics made any difference

- There was a lack of trained clinicians to teach clinical ethics

- There was a prevalent scepticism about whether virtue or character could be taught

### **Key developments**

During the past decade, teaching clinical ethics has spread. A decade ago almost every US and Canadian medical school incorporated ethics teaching into its curriculum, and recently the UK General Medical Council mandated ethics teaching in UK medical schools [10]. The Canadian Royal College of Physicians and Surgeons of Canada requires all residency programmes to teach ethics as a condition of accreditation. An outstanding example of a national continuing education programme is Linda Emanuel's Education of Physicians in End-of-Life Care Project [11].

It is increasingly recognised that the content of clinical ethics teaching needs to be customised to the learner. For example, medical students want ethics teaching to focus on the actual problems they confront [12]. The Royal College of Physicians and Surgeons of Canada has developed specialty-specific curricula for major clinical specialties. Furthermore, those who teach these curricula recognise that dilemmas faced by more advanced trainees are even more specialised - for example, post-mortem sperm donation in urology.

Different clinical ethics teaching methods have been used, including role play, standardised patients, and Internet based cases.

The debate about whether virtue can be taught has continued to rage. Kopelman has argued that the "tension between those wishing to teach values and virtues directly and those who do not wish to do so may be more apparent than real" [13].

Ethics is increasingly part of medical exams and therefore taken seriously by students. For example, the National Board of Medical Examiners in the USA formed an expert committee to review all its examination materials for the amount and quality of questions on end-of-life care. As a result, the Board made a commitment to increase and improve the end-of-life care component of its examinations.

There has been progress in the evaluation of clinical ethics teaching. The ethics objective structured clinical exam has been developed and evaluated [14]. Sulmasy showed that a course in clinical ethics for residents at Johns Hopkins led to long-term improvements in knowledge and confidence [15].

Ultimately, the teaching of clinical ethics needs integrating into the teaching of clinical medicine, so that it becomes, what Hafferty and Franks called the "hidden curriculum" [16].

There has also been progress in strengthening the capacity for teaching clinical ethics. For example, Georgetown University in Washington DC, USA, has held a short course in bioethics for more than 20 years. More recently, the Georgetown Center for Clinical Bioethics in the USA has had a clinical fellows programme for physicians wishing to do advanced work in bioethics. The MacLean Center for Clinical Ethics at the University of Chicago has trained over a hundred clinicians in ethics fellowships; many of these trainees occupy leadership positions in clinical ethics throughout North America. The University of Toronto, Canada, has launched a masters degree, specifically for experienced clinicians with the goal of developing clinician-teachers. Many other centres have also established fellowship or graduate programmes in bioethics.

### **Remaining challenges**

Firstly, we need to develop Internet based teaching modules for clinical ethics. This will improve dissemination of teaching materials and reduce duplication. In addition, as continuing professional development expands, ethics teaching will need to respond to the needs and convenience of practising clinicians. Interactive, web-based formats will facilitate self-learning and distance education.

Secondly, we need to incorporate the increasing knowledge of what is effective in continuing education. Davis *et al* have shown that interactive continuing education sessions that enhance participation and provide the opportunity to practise skills, can change professional practice and, on occasion, health care outcomes [17]. If our ultimate goal is to change practice, we need to go beyond small group learning and to develop opinion leaders in clinical ethics. We also need to develop effective models for teaching clinical ethics at the bedside. Ironically, bedside teaching is potentially the most effective and yet the least studied.

Thirdly, we need to harness the informal curriculum. Clinicians in influential positions who do not respect patients, damage the education of medical students and

residents in a way that no ethics education programme can overcome. We need to develop a culture in our academic programmes and clinical teaching units that is sensitive to the ethical concerns of patients and families. Ultimately, this will occur if we recruit the right people for ethics training, and hang on the coat tails of their success.

Fourthly, medical educators should pay attention to character formation because character is so central to moral life. This is a more complex subject than simply teaching about virtue. The key, of course, is role modelling by faculty members, and building a sustainable community of clinicians focussed on the ethical concerns of patients and families. Sadly, both are lacking in many of today's medical schools.

Fifthly, we need to focus more on evaluation. Performance in clinical ethics should be part of the evaluation process for physicians at all levels. For example, in-training evaluation reports for residents should contain an item about how the resident performed with respect to challenges in clinical ethics. However, evaluation measures need to be studied further in terms of their reliability and validity. The focus should be on measures that capture what happens at the bedside. Data should be sought from teachers of physicians and other members of the health care team, as well as from patients and families. Finally, medical educators should pay more attention to the evaluation of character. Every medical student knows which of his classmates he would not trust to care for him or his family, yet the faculty seem totally ignorant of - or unwilling to do anything about - those students whose character deficiencies need discovering and addressing.

Finally, we need to strengthen our capacity to teach ethics. Teaching clinical ethics at the bedside requires staff with both clinical and ethical skills, and in most universities there are not enough people with such skills. Academic health science complexes need to develop faculties for teaching clinical ethics. The strategy should extend well beyond those with formal ethics training to include clinical teachers. If clinical ethics is best learned at the bedside in the care of individual patients, clinician teachers in general, and not clinical ethicists, will need to have the skills to recognise and fully exploit the moments in patient care that lend themselves to teaching clinical ethics.

### **Ethics committees and consultations**

#### ***Our earlier observations***

Ten years ago we outlined three key functions of ethics committees and consultants: education, institutional policy development, and case consultation.

With regard to ethics consultation, we argued that:

- The central goal is to improve patient care and patient outcomes
- The ethics consultant must be ethically and clinically competent, although not necessarily a physician
- The consultant's recommendations are suggestions that the referring physician may choose to accept or reject

We highlighted three key dangers of ethics consultations and committees:

- Abrogation of moral decision making by the referring physician
- Usurpation of moral decision making by the ethics consultant
- Diffusion of responsibility within the ethics committee

We outlined four models of ethics case consultation:

- Pure committee model (no ethics consultations, just committee work)
- Committee member as consultant (a committee member performs consultations but these are not systematically reviewed by the ethics committee)
- Post-facto committee review (the committee reviews the consultations after they have been performed)
- Pure consultation model (no ethics committee, just an ethics consultation service)

Finally, we highlighted the limited evidence base on which ethics committees and consultation services had been developed, and called for the effectiveness of these programmes to be evaluated.

#### **Key developments**

The key development in the last decade was the American Society for Bioethics and Humanities' report on 'Core Competencies for Health Care Ethics Consultation.' Co-chaired by Robert Arnold and Stuart Youngner, the report described core competencies for ethics consultation in health care, but rejected accreditation of programmes or certification of individuals or groups to do ethics consultation [18].

The 1990s also saw the clinical ethics movement called into question by two amusing but incisive articles. In

1997, in "When we were philosopher kings," published in *The New Republic*, Ruth Shalit took clinical ethics to task for its lack of educational standards, its lack of evidence of effectiveness, for its "attitude of superior virtue", for confusing the empirical and theoretical, and for "the matter of ethics-for-hire [19]."

In the same year, a Lancet editorial concluded:

"...the ethics industry needs to be rooted in clinical practice and not in armchair moral philosophy. Debate on ethical matters is as much an integral part of everyday doctoring as choosing the best treatment for patients. Departments of ethics that are divorced from the medical profession, wallowing in theory and speculation, are quaintly redundant [20]."

There are important truths in these criticisms, which call for heightened humility, self-questioning, and evaluation on the part of clinical ethicists.

Clinical ethics also entered the field of quality improvement: the Tavistock Group described a set of principles that facilitate a team approach to care [9]; Joanne Lynn led a quality improvement collaboration on end-of-life care through the Institute for Health Care Improvement in Boston, USA [21]; and Joan Teno developed a toolkit to measure quality of end-of-life care [22].

Another important development has been an increasing focus on conflict resolution in clinical ethics, particularly in the areas of end-of-life care and cultural difference. This focus is likely to increase over the next decade.

#### **Remaining challenges**

In our view, the most exciting prospects for ethics committees and consultants involve integrating them into the quality improvement culture of health care organisations. For example, we hope clinical ethicists will develop report cards for health care organisations on the quality of end-of-life care. The approach of the Picker Institute in Boston, USA, to care through the patient's eyes represents an important hint of future possibilities. We hope clinical ethicists will spend time with patients, understand their concerns, and feed these back to clinical teams and senior management to harness the opportunities for improvement. A decade ago, Rabbi Julia Neuberger, now Chief Executive of the King's Fund in London, did just that with bone marrow transplant and other cancer patients at Beth Israel Hospital in Boston (Neuberger J, personal communication). Unfortunately, this important line of clinical ethics has not yet been further developed.

A second key challenge relates to organisational accountability. How should we respond if a board member of a health care organisation asks, "Is this an ethical organisation?" In response to this simple but critical question, we should be able to describe an accountability framework of policies, processes, and practices, and provide empirical data with respect to certain indicators. Sadly, we are nowhere near being able to provide a comprehensive answer to this question. The US Joint Commission on Accreditation of Health Care Organisations has recommended that some mechanism for institutional ethical accountability be developed. However, there are at present no standards to encompass the wide ambit of clinical, managerial, and academic activities one would want to examine in a comprehensive "ethics audit" in response to the Board member's deceptively simple question. In short, what is needed is an accountability framework or ethics infrastructure for health care organisations?

Third, it is increasingly recognised that the capital assets of health care organisations involve not just buildings and equipment but also the people who work in the organisation. Although clinical ethics takes seriously the need for education of health professionals, and has at times used modern methods of continuing education, it has not looked upon its task as one of strengthening capacity both by hiring ethicists and by building the skills of health workers throughout the organisation. For example, one can identify few systematic efforts in health care organisations that aim to develop the skills of health workers to address pressing clinical problems such as medical error, end of life care, and the like. Ideally, health care organisations will have: a workforce able to address common ethical issues without the assistance of a clinical ethicist; and systematic strategies of capacity building and measures of capacity, with respect to clinical ethics.

A fourth challenge is further work on organizational ethics, which is in the earliest stages of conceptual and methodological formation. Organisational ethics is an exercise in collective accountability. It has to do with persons acting together on behalf of some institutional goal. It is concerned with defining an ethically defensible mission, implementing that mission, and allocating responsibility at all levels of institutional life for preserving the fidelity to the mission. Hospitals are examples of institutions acting as moral agents, fulfilling the promise to serve the needs of the sick in the community. What is the source of this obligation and how is it distributed at all levels from trustees, administrators, professional staff and non-professionals? How are conflicts of obligations resolved? Should organisational and clinical ethics committees be separate, institutionally related in some way,

or combined? What is the role of professional organisations? And do they have ethical responsibilities over and above the welfare and self-interests of the professionals they represent? These are some of the questions organisational ethics must address.

Finally, although important improvements have occurred in clinical ethics processes, the goal of improved clinical outcomes has not been achieved. We find this conclusion disappointing, and urge our colleagues in clinical ethics to redouble efforts to demonstrate improvements in patient outcomes related to clinical ethics activities.

### **Future directions in clinical ethics**

#### ***Our earlier observations***

Ten years ago, our predictions for future directions in clinical ethics were as follows:

- New ethical challenges posed by advances in biotechnology
- Maturation of clinical ethics by strengthening the research base and developing graduate programmes and fellowships
- Emphasising the intersection between clinical ethics and health policy, including a focus on ethics of health care institutions and health systems
- Increasing public education and involvement
- Developing the conceptual foundations of bioethics
- Changes in the doctor-patient relationship

#### **Key Developments**

In biotechnology, our prediction of ethical challenges is as true today as it was a decade ago. In the past decade, there were major developments in biotechnology: cloning; xenotransplantation; stem cells; and the completion of the sequencing phase of the Human Genome Project. These developments occupied the focus of the US National Bioethics Advisory Commission, the Nuffield Foundation in the UK, the Organisation for Economic Co-operation and Development (OECD, Paris, France), the World Health Organisation, and the Rockefeller Foundation. They highlighted important issues about our humanity, the social tolerance of risk, and attitudes towards globalisation. Weijer and Emanuel have carried out helpful conceptual work on genetic research [23]. In the next decade, the social challenges of biotechnology will be even greater.

In terms of maturing, clinical ethics has succeeded in many ways: it has involved clinicians; it has penetrated medical organisations and institutions; it has spawned important research and teaching efforts; and it has created new career opportunities for physicians and other clinicians. However, if the goal of clinical ethics is to improve patient care and outcomes, there is scant evidence that this has been achieved. Much more needs to be done to examine clinical ethics against this goal.

In terms of health policy, Ubel and Nord have performed experiments on the trade off between equity and efficiency [24]. And Holm has astutely highlighted that substantive solutions to priority setting are elusive and that more attention must be paid to the process of decision making [25]. Daniels and Sabin have made an enormous contribution to the area of decision making by developing "accountability for reasonableness" as a model for priority setting [26]. Hope has described actual priority setting in the Oxfordshire Regional Health Authority in the UK [27] and Ham has distilled the lessons of international attempts at priority setting [28]. Hadorn has developed methods of clearing waiting lists through setting priorities based on clinical indications [29]. By developing a method to rate the health, financing, and responsiveness of health systems, the 2000 World Health Report has stimulated a new discussion about fairness of health systems around the world [30].

Public education in clinical ethics has grown tremendously, although public consultation and involvement has lagged behind. One of the most remarkable developments is the interest of major news organisations in ethics. The leading voice on ethics in the media has been Art Caplan. Caplan's work in making bioethics issues understandable to the public has been a major contribution to the field. Methods of public consultation and public involvement remain elusive. We predict these matters will gain more attention, and hopefully more progress, in the next decade.

Without question the major contribution to the conceptual foundations of clinical ethics has been the continued refinement of 'Principles of Biomedical Ethics,' by Tom Beauchamp and Jim Childress [31]. The text by Jonsen, Siegler and Winslade, based on a clinical, casuistical approach, has continued to help those interested in clinical ethics [32]. Narrative ethics has developed as an important complementary method. Feminist theory has developed during the past decade and, importantly, feminist scholars are now applying their analyses to matters "beyond reproduction." There have also been developments in virtue ethics, hermeneutics, and phenomenology. Somehow, all these will need to be reconciled and put

into some rational order and relationship with each other.

Clinical ethics is not founded in philosophy, law, or theology but, instead, is a sub-discipline of medicine, centring upon the doctor-patient relationship [33]. After 20 years of clinical ethics, the doctor-patient relationship is in worse shape than it was when the field began. The main theme in the doctor-patient relationship during the 1990s in the USA was bureaucratisation by managed care. Despite the impressive achievements described elsewhere in this article, it is troubling that the doctor-patient relationship is deteriorating even as we congratulate ourselves on how well clinical ethics has progressed. If the doctor-patient relationship is the foundation of clinical ethics, how well can the field be doing, and how well will it do in the future, if the foundation is not solid?

#### **Remaining challenges**

The main ethical challenge today is the enormous inequities in global health [34]. To date, clinical ethics has primarily been a phenomenon of developed countries, but the development of global health ethics has begun and will surely pick up momentum. Van Rensselaer Potter coined the term "global bioethics" [35]; Ruth Macklin has examined the universalisability of values [36]; Hans Kung and Amartya Sen have laid important conceptual foundations for global bioethics [37, 38]; the US National Bioethics Advisory Commission and the Nuffield Council on Bioethics in the UK have ongoing studies of research ethics in developing countries [39, 40]; the World Health Organisation and the Fogarty International Center of the National Institutes of Health have appointed staff ethicists; the Fogarty International Center has also funded grants to strengthen capacity in ethics in developing countries; an International Association of Bioethics, and a Global Forum on Bioethics in Research have been formed; international research has been conducted in relation to human rights, women's health, and transplantation; the World Health Organisation has developed Guiding Principles on Medical Genetics and Biotechnology [41]; and the Human Genome Organisation Ethics Committee, chaired by Bartha Knoppers, has developed guidelines on benefit sharing [42].

When we revisit clinical ethics a decade from now, we hope to be telling you about the World Health Report on Global Health Ethics written in 2006. The report will address important global issues in bioethics, including biotechnology, research ethics, end-of-life care, priority setting, women's health, child health, mental health, and rehabilitation ethics.

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## Responses

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