

ORIGINAL ARTICLE

Absent virtues: the poacher becomes gamekeeper

T Koch

Since its inception, bioethics' principled stance has been to argue against paternalism and elitism, and for an inclusive ethical perspective. But at least in North America, the growth of bioethics as a special area of applied ethics has created conflicts within the field itself. Those who, a generation earlier, argued against paternalism and for both professional and public accountability in medical decision making are now part of the decision making process. Too often, it is argued in this paper, their allegiance is to the employer, or to a view of medicine that is institutionally based. As a result, it is suggested by this review, medical ethicists have adopted the perspective that, in the early 1970s, they most criticised. The answer, it is argued here, is to revisit a lexicographical ordering of responsibility in bioethics, one that recognises professionals as individuals with responsibilities, as citizens with a public posture, and finally, as professionals involved in the process of medical decision making.

In the 1960s, a group of medical amateurs trained in moral philosophy joined with other US citizens in a national discussion on how best to allocate scarce medical resources. The debate over limited access to the then new dialysis machines in Seattle, and the resulting necessity of rationing that resource for patients with progressive kidney disease, in retrospect marked the beginning of modern bioethics.¹ Others, of course, date the birth of bioethics slightly differently. By the middle of the 1970s, what had begun as a response to a specific problem became a more general programme for addressing a range of issues involving medical delivery, medical practice, and health care distribution. The eventual result was, in Edmund Pellegrino's words, "the subjection of the entire corpus of medical ethics to serious philosophical inquiry".²

As Binmore put it: "Moral philosophers typically hold that the purpose of their discipline is to uncover universal principles that we all ought to follow when interacting with our fellows".³ It is perhaps not surprising, therefore, that the marriage of philosophy and traditional medical ethics (one defining physician responsibilities to the patient) resulted in a limited set of principles⁴—autonomy, benevolence, justice, non-maleficence, etc.—presumably capable of addressing problems of medical delivery and practice irrespective of social, cultural, or economic disparities.⁵ Certainly not all moral philosophers—or all bioethicists trained in moral

philosophy—seek to describe universal moral principles. Act-utilitarians, casuists, and virtue ethicists—for example, participate through other discourse modalities. But since the 1970s, principlism has been the basic, default approach to bioethical debate over medical policy, research paradigms, and medical case review.⁶

From the beginning, bioethics' principled focus on patient autonomy in a benevolent and publicly transparent system of just medical delivery placed it in opposition to a more traditional, professional medical ethic which emphasised the primacy of physician responsibility in the physician/patient relationship. Indeed, the discipline's ascendancy occurred at the same time as the practice of medicine was shifting in the USA from an individual to a corporate, managed care environment.⁷ "As physicians and other health care professionals become more and more business people," Lowry writes, "fiduciary concerns diminish or disappear and are replaced by [at best] the ethics of the good and honest businessman related to the customer or client merely by explicit contract or understanding" (Lowry EH,⁷ p 1515). Similarly, the moral philosophers who participated in the 1960s debates as citizens have been transformed into academic or corporate professionals for whom "what is right" may take second place to "what is institutionally (or professionally) acceptable".

What has been lost in the process is at least as critical as whatever may have been gained. Most importantly, the individual, personal accountability of health professionals—the *sine qua non* of the older, medical ethic—has been diminished where not wholly sacrificed to the institutional perspective of contemporary bioethics. Rather than a more rigorous and socially inclusive response to medicine's technical development, it offers a professional perspective that may be less responsive to individual autonomy and patient need than the traditional medical ethic it replaced.

In addition, the critical, independent voice of the 1960s philosopher involved as a citizen in medical debates has been submerged in the increasingly official discourse of bioethics practitioners. In many cases this has meant that debates on appropriate practice and procedure often proceed without public input, without the general contribution of the citizenry at large. The educated and involved citizen has given way to the professional expert, often on the assumption that the public can neither understand nor judge complex issues of bioethical concern. And yet, as I have argued elsewhere, despite the technical issues involved in current medical debates, public citizens can be involved in both general

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Accepted for publication
27 June 2003

J Med Ethics 2003;29:337–342

and specific debates over appropriate medical practice and procedures in contemporary society.⁶

As a general result, contemporary bioethical practice appears to have appropriated the worst characteristics of the medical ethic that philosopher/ethicists criticised a generation ago, which was professionally biased, often unacceptably paternalistic, and spoke not for the patient or society at large but for vested professional and institutional interests. It is not simply that, as François Baylis noted, moral heroism is a largely absent virtue in bioethics.⁸ More critically, this paper argues, the absent virtue following from the failure of contemporary bioethics is systematic and fundamental rather than, as others have argued, procedural and peripheral. The very nature of its disciplinary discourse has largely obscured the pervasiveness of bioethics' flawed approach and increasingly biased application.

This argument presents a distinct reading of the issues that currently engage bioethical debate. It suggests bioethics' increasing institutional legitimacy has engendered a professional perspective that is antithetical to the broader ethos of its original social philosophy and posture. As a systematic inquiry into issues of medical provision and treatment, its address has been limited by the theoretical form of the principled discourse it generally advances. The problem can be perceived through a review of current, problematic cases discussed in the general literature. But as I will argue, the heart of the problem lies in the questions the profession no longer thinks to ask, and the parameters of discourse its practitioners reflexively accept as a condition for funding and professional standing.

The Cleveland experience

On 13 April 1997, the national CBS TV show *60 Minutes* aired a segment on transplant harvesting protocols at the Cleveland (Ohio) Clinic Foundation (CCF). "Not Quite Dead" reported that the CCF's non-heartbeating organ donor (NHBD) protocol, which "could have been regarded as homicide under Ohio law", was under investigation by local criminal prosecutors.⁹ The protocols in question involved the use of drugs (Heparin and Regitine) which facilitate organ harvesting but may hasten the death of the donor.

As a result, CCF bioethicist George Agich told a *New York Times* reporter that the *60 Minutes* story was "tarnishing the whole organ procurement program and the donation effort".¹⁰ Agich later blamed both "media sensationalism," and the bioethicist who brought the issue to outside examination, for the public scrutiny that contributed to the policy's withdrawal. The lesson he drew from these events was that: "the future of bioethics may be not in the media spotlight, but in shadows where the quality of everyday patient care is enhanced".¹¹

Background

Peggy R B Bargholt, a former education coordinator at LifeBanc, the local organ transplant procurement agency, received the NHBD policy statement from LifeBanc for use in a bioethics course taught by Dr Mary Ellen Waithe at Cleveland State University. In the subsequent classroom discussion, students expressed concern that the clinical protocols authorised the use of drugs that would hasten the death of persons to advance the collection of their organs. These concerns led Ms Bargholt and Dr Waithe to request a review of the NHBD protocols from the appropriate state body, Ohio's State Board of Pharmacy. That review was later forwarded to Carmen Marino, first assistant Cuyahoga County (Ohio) prosecutor, who opened the official investigation which was the focus of the *60 Minutes* story.

Agich later took Dr Waithe to task for not bringing her concerns to CCF or LifeBanc officials before submitting them to official review. "Cooperation and collegiality, often

optional in traditional academic contexts, are indispensable in bioethics," he insisted, (Agich G,¹¹ pp 270–1). Dr Waithe, however, rejected this argument in a letter published in the *Cleveland Plain Dealer*. "If you have reason to believe that someone plans to violate the law," it said, "you report them to the authorities. You don't sit down for a nice chit chat."¹²

In effect, Agich argued for the primacy of a collegial association perhaps similar to that reflected in sacrosanct (and legally protected) hospital mortality and morbidity review panels. Morally and legally, however, a citizen who believes a law is being violated—or a serious wrong is being committed—is obliged to inform the authorities. Unless there is a legal veil (as exists for priests—for example) to do otherwise is to be legally and morally complicit in the wrongful act. Dr Waithe and Ms Bargholt placed their responsibilities as citizens above their respective roles as bioethicist and former transplant agency employee.

Their actions argued that we are first and foremost citizens and that our obligations as citizens take precedence over professional obligations. To insist first on a professional and collegial responsibility would reverse the fundamental ethical equation of citizenry and the individual's moral standing in society.

Agich's condemnation of the public reportage of the CCF case was similarly troubling (Agich G,¹¹ p 273). Legally, graft organs supplied voluntarily by citizens or their survivors are a public resource (NOTA, 1984).¹³ The system is based on public involvement and public trust. Thus public interest in a criminal investigation into harvesting policies of the collective resource is clearly legitimate. More practically, the life and health of fragile citizens is an appropriate subject of public scrutiny. As one bioethicist asked in another context: "if information is the vehicle of community solidarity, and the media serve as the community's representatives, might their surrogate claim on information carry greater moral weight than many of us have been inclined to acknowledge?"¹⁴ To argue for the shadows rather than public review is to argue professional over public spheres of influence, a prior obligation to professional over public discourse and debate. To agree with Agich, (and many perhaps do) insisting privately if not publicly that the general public does not understand what bioethicists perceive, is to insist upon a perspective antithetical to bioethics' populist origins, and to the bioethicist's primary duties as a citizen.

Implications

Perhaps most telling about the CCF case was its failure to engender a serious debate over the ethics and moral legitimacy of the US organ transplantation system itself. In the 1960s, the ethical debate over allocation of scarce dialysis beds in Seattle rapidly became a broader debate about the more general problem of scarcity at the scale of the nation. In the 1990s, however, legal review of the NHBD protocols in Cleveland—then being used by more than 20 US organ transplant facilities, (Agich G,¹¹ p 269; see also the papers by Spielman and Verhulst¹⁵)—resulted in no broader response by bioethicists or the media. If the NHBD protocols were murder in Ohio, why not in those other states? Also, if Americans were repelled by the procedure at the CCF, why was there no cry against the general practice?

Interestingly, while a growing literature questions the brain death criterion underlying NHBD protocols (harvesting is acceptable because the lack of brain activity means the donor is a non-person, heartbeating but "dead", see—for example, the papers by Fisher and Truog),^{16 17} its relation to the problematic NHBD protocol has not been well argued in the literature. Nor has there been a sustained discussion over the inequalities and inequities inherent in the US organ transplant system. As I have argued elsewhere, the ethnic

and economic disparities embedded in the US system are pervasive and systemic.¹⁸ Promises of a just allocation to all needy citizens are unmet. And yet bioethicists in the 1990s, unlike their 1960s progenitors, have not chosen to address the central issues underlying either NHBD protocols or the greater transplant and health delivery systems. The broader perspective of ethical and moral behaviour as a social concern has been lost to the review of technical processes and policies irrespective of such fundamental concerns. Simply, it is safer to criticise the policies of distant countries such as South Africa,¹⁹ India or China²⁰ than the financially remunerative and professionally popular policies of one's own nation and home institution.

RESEARCH VERSUS CORPORATE ETHICS

One reason for this may be the enormous personal and professional cost that arises when lucrative hospital and university programmes are challenged. In this regard the Canadian case of Dr Nancy Olivieri is instructive. Olivieri was dismissed from her position at The Hospital for Sick Children (HSC), Toronto, after allegedly violating contractual privacy agreements with a private drug company, Apotex Inc, which had hired her to conduct clinical trials of a drug they hoped to market.

In 1992, Olivieri and Dr Gideon Koren, a clinical pharmacologist, were funded by Apotex to carry out a clinical trial of Deferiprone as a treatment for thalassaemia major. At that time the only way to rid patients with this disease of a potentially fatal iron build up in cardiac and hepatic tissues was an overnight IV infusion of the drug Deferoxamine.²¹ If Deferiprone would permit this costly and invasive procedure to be replaced with a single, daily, oral medication it would be a vast improvement over the older technique.

By 1995, Dr Olivieri's research indicated that not only was the drug ineffective but that in some cases it appeared to result in liver damage. The *Ottawa Sun* reported that: "By the summer of 1995, she insisted her data revealed the drug was ineffective".²¹ For a clinical statement of the researcher's perspective on the data see Olivieri, *et al.*²² She reported her findings to the hospital and the company, urging trials be ended both in Toronto and at other test sites. Apotex officials said her findings were not supported by other research site results and warned that public disclosure would be actionable. "The firm threatened a lawsuit and terminated her clinical drug trials", reported the *Toronto Sun*.²³ A senior Apotex vice president was quoted as saying: "We told her should she present information that is wrong that we are prepared to take action against her".²³

The Hospital for Sick Children at first appeared to blame Olivieri for placing herself in a conflict of interest by signing a research contract whose standard privacy clause prevented her from publicly criticising the drug.²⁴ That report, which seemed to absolve the institution of responsibility in the dispute, was itself condemned when 140 hospital employees signed a petition demanding "a full, independent inquiry" into the controversy.²⁵ Hospital officials later admitted they had made mistakes and regretted the institution's lack of legal and moral support for Olivieri in her fight to present her findings.²⁶

For its part, Apotex consistently dismissed charges that it sought to silence Olivieri and asked only that she admit to conflicting evidence from a variety of trials. "She makes it sound like we're trying to get a toxic drug on the market and we're trying to suppress that information", an Apotex official told journalists, "and that's wrong".²¹ In public interviews, however, Olivieri described herself as "terrified I would now not be able to tell parents, patients, the truth".²³ She insisted her findings were correct and that neither patients nor physicians were adequately informed "about the long term

lack of efficacy of the drug in many or most patients and, most important, about the potential risk of danger to the liver and heart associated with this therapy".²⁷

At one level, the Olivieri case is another example of the opposition between individual and institutional moralities. The Olivieri research team's primary, self stated concern was "that patients and their physicians who are participating in drug trials or programmes of 'compassionate' use of Deferiprone have not been adequately informed about the long term lack of efficacy of the drug in many or most patients" (Brittenham GM, *et al.*,²⁷ p 1711). Not to have gone public would have violated the first axiom of traditional medical ethics ("first, do no harm", "a doctor's moral duty is to put patient safety first")²⁶ as well as the more modern advocacy of informed choice resulting from full disclosure to patients and their attending physicians. Going public meant, however, that her career within her hospital, and her reputation as a researcher, were placed in jeopardy.

Olivieri reported her findings to the US Food and Drug Administration (FDA) and in a brief submission to the *New England Journal of Medicine*.²⁷ While the clinical debate in that venue was vigorous,²² a sustained and public discussion about the broad ethical ramifications has been more muted. Whatever their institutional role, Hospital for Sick Children (HSC) bioethicists did not take a vigorous public stand on the Olivieri case. Privately but not publicly—and not for attribution—at least one has acknowledged to this author pressure from their employer to minimise adverse publicity, and perhaps, protect its standing as a research site. While none would speak publicly regarding this pressure, the Hospital for Sick Children's director of blood and cancer research, Dr Brenda Gallie, did criticise the hospital's handling of the case, adding to a news reporter that: "So I guess I'll get fired on that one, too".²¹ It appears likely, in other words, that hospital bioethicists were in a position analogous to Olivieri's. The fact of their employment apparently served as a restraint upon their ability to publicly comment on a situation with broad ethical and legal ramifications for hospital research and patient care. Unlike her, however, they choose to remain in "the shadows," to use Agich's phrase, rather than in the professionally dangerous arena of public and professional debate.

The Gelsinger case

There are strong parallels between the Olivieri team's battles and the better known US case of the death of Jesse Gelsinger during a clinical drug trial. Others have considered this case—and that of asthma drug test patient Ellen Roche—as emblematic of procedural problems in ethics review procedures.^{28 29} From the perspective of this article, however, the issues raised are more central.

An 18 year old Tucson, Arizona resident, Jesse Gelsinger, died in September 1999 at the University of Pennsylvania hospital after serving as a test subject in research on the efficacy of a genetically engineered experiment treatment. He was recruited for the experiment because he was born with ornithine transcarbamylase deficiency syndrome, a liver disorder. Gelsinger's father testified at a congressional hearing that he and his son had not been told about potential risks involved in the experimental procedures. "It looked safe. It was presented as being safe," Paul L Gelsinger said. "Since it would benefit everybody, I encouraged my son to do this." But, he told senate investigators: "This was not as it was presented."³⁰

Like the CCF case, this one raises the relation between public knowledge, patient information, and conflicting professional responsibilities. And like the Olivieri case, it presents an invaluable insight into the relation between, on the one hand, pressures on institutions and their researchers

to develop new drugs and new procedures, and on the other, the possible harm resulting to uninformed (or under informed) patients. Of equal importance, however, are the restrictions that may limit bioethicists who are paid by pharmaceutical companies to serve on ethics review committees. The pervasive and lucrative use of bioethicists to review drug protocols introduces what Carl Elliott calls a “business model that undercuts arguments for [bioethical] professionalism”.³¹

While the Gelsinger case has been discussed as an example of problems in the structure of clinical review committees, its wider context has gone largely unconsidered by bioethicists. In US senate hearings, a witness from the National Institute of Health admitted that despite federal regulations requiring the reportage of adverse events in gene therapy, over a seven year period only 39 of 691 “adverse events” in this research were, “reported in a timely way”.³⁰ The Gelsinger case was neither an isolated case nor symptomatic of a simple problem in the structure of ethical review committees. Rather, it reflected a general refusal to comply with legal guidelines and report dangerous outcomes resulting from research supposedly reviewed, and perhaps monitored, by committees which, in many cases, pay bioethicists to take part in their deliberations.

THE LATIMER CASE

A final example, again Canadian, exemplifies the manner in which bioethicists tend to focus their critique on the aspect of cases that is least contentious, least publicly relevant, and safest for them professionally. In 1993 Canadian farmer Robert Latimer killed his 11 year old daughter, Tracy, because he believed she had suffered sufficiently from both the cerebral palsy (CP) that afflicted her and the invasive medical treatments she received to ameliorate its effects. His 1994 conviction, which carried a mandatory life sentence with no eligibility for parole for 10 years,^{32–33} was then overturned on procedural grounds.³⁴ After being again convicted at a second trial, his mandatory sentence was appealed to the Canadian Supreme Court.³⁵ Latimer’s defence, one that has aroused widespread public (and professional) sympathy has been that he acted out of compassion, out of love. His daughter’s extreme spasticity no less than the severity of attempts to palliate it—including surgical interventions—were simply too much for him to watch passively. On news shows and in hospital rounds, some bioethicists have supported Latimer’s actions, arguing that this is a case in which a loving surrogate acted in the best interests of a patient whose life quality was unacceptable.

In the resulting debate, issues of autonomy, futility, and life quality have been much discussed. The generally principled discourse of Canadian bioethics has almost entirely avoided the primary question that would have been raised first under a more traditional medical ethic: what else might have been done for the patient? Beginning in the late 1980s, a new treatment was developed for patients whose CP caused spasticity. Summarised in a 1991 article in the *Journal of the American Medical Association (JAMA)*, it involved delivering the drug Baclofen intrathecally, directly into the spinal canal.³⁶ In that year the US Food and Drug Administration (FDA) approved use of a computerised pump to deliver measured doses of the drug into the spinal canal over time, providing long term relief for patients like Latimer.³⁷ The month after Tracy Latimer was murdered a *JAMA* article reported positively on the use of the intrathecal pump delivering Baclofen as a means of offering long term relief for a range of patients with “spasticity of cerebral origin”.³⁸

The potential of this technology, then being used in Vancouver, BC, Canada, at the time of Tracy Latimer’s death,

is critical. Robert Latimer and the Canadian public sympathetic to him had been told no non-surgical procedure was available to palliate his daughter’s painful physical condition except, perhaps, radical surgery. Both his act and the public sympathy it engendered were based on the assumption of her continued physical suffering for which no acceptable palliative treatment was available or expected. That a technique existed, was being used elsewhere, and had been shown to be efficacious changes the parameters of the debate.

Assuming it was unavailable in Saskatchewan but available elsewhere, the potential of an intrathecal pump to relieve spasticity shifts the moral onus for Tracy’s death shifts from Latimer alone to her provincially funded health care providers. If the procedure was known and elsewhere available why was it not available in the province of Saskatchewan and offered as a potential treatment in this case? A strong legal as well as ethical argument exists that failure to provide adequate care is not only ethically suspect but legally a “predicate act” directly resulting in the subsequently criminal action.³⁹ Morally, the argument is even stronger. If the intrathecal delivery of Baclofen was offered but rejected by Latimer, his stature as a man protecting his daughter from painfully invasive surgery would have been radically diminished.

Why did Canadian bioethicists not consider this aspect of the case from the start? Indeed, was there not an obligation for them to raise the issue of treatment in public discussion of the Latimer case? The answer seems to be that the reflexive response by bioethicists considering this nationally contentious case has been principled and not practical, ethical rather than medical, from the start. When I raised the issue of treatment in rounds on the Latimer case at the Hospital for Sick Children in Toronto I was told it was impolitic. It was off the table. Simply, it was easier and professionally safer to argue the principled rather than the practical, the ethical rather than the morally medical.

DISCUSSION

The “lively” discourse of what Albert Jonsen has called the “demi-discipline” that is contemporary bioethics⁴⁰ is thus constrained in a number of ways. Issues of collegiality, economic self interest, and the threat of professional censure divert bioethicists from their traditional role as principled amateurs acting as public surrogates. Bioethicists themselves have become too often what their progenitors most detested, individuals largely devoid of self conscious social agency and responsibility . . . gamekeepers who were once poachers themselves.

As a direct result, professional bioethicists safely produce endless papers deliberating approaches to medical rationing but rarely critique the governments and industries that impose unnecessary scarcity upon the delivery of medical services.¹⁸ Bioethicists endorse *ad nauseam* the ideal of informed consent without considering the widespread functional illiteracy that results, in the USA, from limits imposed on educational funding at every level. Professionals have written hundreds of papers on the ethics of cloning (and hundreds more on rare conditions like anencephaly) but relatively few on issues of public health—for example, firearm related deaths in the USA⁴¹—that cost society thousands of lives and millions of treatment dollars annually. Bioethicists debate endlessly how to find the best (most moral and ethical) medical students without addressing the social and economic environments that turn even the most virtuous young physician or nurse into a professional for whom ethics is a chore rather than a moral duty.

A revised bioethics

What would be required for bioethics to be an effective and moral voice? First and foremost, perhaps, recognition by its practitioners and theoreticians that medicine and medical practice occur within a social structure and organisation that is critical to ethical as well as clinical practice. In 1848 the German anatomist and pathologist Rudolf Virchow, investigating a typhus epidemic in Upper Silesia, concluded its cause was the social and political subjugation of the region's Polish inhabitants by the dominant Prussian government. To combat the spread of such epidemics, Virchow said, required attention to the broader living conditions of the populace.⁴² In 1854, John Snow's investigation of a cholera outbreak in London's Soho district led to an understanding of sewage and sanitation as causative agents in cholera's spread.⁴³ An expanded role for public health as a means of addressing specific diseases was the direct result.

To argue that bioethicists accept the centrality of a social context is not to argue that bioethicists become sociologists. Rather, it is to insist that a robust ethics applicable to modern medicine must at the very least entertain the lessons of mid-nineteenth century public health and medicine in its attempts to grapple with issues of twenty first century practice. The broader social venue of contemporary medical concerns is at least as equally important as the principled consideration of clinical issues bioethicists seek to address.

As a corollary, it is important that practitioners accept the twentieth century lesson which insists, in Richard Lewontin's words, that we recognise "biology as ideology".⁴⁴ The mechanisms of clinical investigation, health care delivery, and medical training all exist within ideological contexts that affect the resulting science and its applications. The debate over disability within the contemporary literature offers a simple but effective example of the degree to which biological difference may, depending on one's ideology, be interpreted very differently, with results that will greatly affect the acceptance or rejection of persons of difference.⁴⁵ In the current debate over genetics and genetic testing this is especially important.

For the professional bioethicist him or herself, what is required is a lexicographical ordering of responsibility that acknowledges the primacy of his or her obligation as a person and as a citizen. The standing of moral philosophers in the 1960s debate over medical rationing resulted not from their specific expertise, although that certainly contributed to the debate, but from their standing as educated citizens involved in a public discourse. More generally, the professional role of bioethicists (and other medical professionals) in current medical policy debates stems not solely from their academic or clinical expertise but more fundamentally from their role as educated citizens participating in a democracy.

Only with those obligations met are their responsibilities, first to patients and *then* to colleagues and employers, given full sway. At present those who insist upon this ordering—Dr Waithe and Dr Olivieri—for example, are chastised for their choices. While they appear to be the exception—the "heroes" whose absence Francois Baylis, cited earlier, lamented—the lesson they present is critical.⁸ In law and in society we stand first as citizens and only secondly as professionals, except where a specific social exemption, priests—for example, is acknowledged. To insist upon any other ordering of our responsibilities is to deny the primacy of our individual roles within society.

It is common for bioethics instructors to use the example of a Nazi physician torn between treating a Jewish patient and thus losing his or her medical post, and the chance to treat hundreds of other people, as a bioethical dilemma. It is uncommon, however, for them to argue the same lesson from the perspective of a British physician who must choose which

patients will be treated and which will be refused because of governmental funding restrictions.⁴⁶ Nor do we argue the same point from the perspective of a US emergency care doctor who may stabilise but cannot truly treat any of the more than 36 million citizens without health insurance. In such a context the bioethicist who speaks for the system, who argues the logic of rationing⁴⁷ and the efficacy of its utilitarian underpinning, is as culpable as the German physicians who, in the classical dilemma, we condemn in retrospect.

None of this will require the jettisoning of the principled discourse which is Western bioethics's *raison d'être*. At best, perhaps, it argues for what Wolfe called a more pragmatic bioethics, capable of addressing medicolegal issues as they occur in a complex social and economic environment.⁴⁸ In addition it recognises that the universal applicability of bioethical principles is difficult to assert in an increasingly global and multicultural world.⁵ This is not simply experientially true but is importantly true because of the diverse social and economic contexts of societies for whom we seek to dictate practice. To the extent that bioethicists believe in principled discourse, however, the onus for principled application lies with the practitioner's ability both to define carefully the principle and the prerequisite social context required for its implementation. To argue principle as if it is divorced from anything but reason is to insist upon abstract logic divorced from practical circumstance as a viable tool for twenty first century considerations.

CONCLUSIONS

In the 1960s medical ethicists presented the voice of the educated citizen/philosopher, one that was articulate and clear. Its perspective was that of the medical amateur, of the citizen who had thought deeply about issues and policies affecting all citizens concerned with their health care. That has been lost in the rush to professional standing, in the push to create departments, endowments, policies, and research programmes. What has been gained as a result is a professionalism that comes at the price of the responsible posture early bioethicists of forty years ago urged upon the then dominant medical community.

The problematic nature of the resulting professional paradigm is reflected in a range of contemporary cases, and in more general critiques of the field. To argue the failure of contemporary bioethics is not, however, to argue against bioethics. Rather, it is to insist that the discipline must be reconstituted in a manner that rectifies its more glaring contemporary limits. These include an acceptance of the primacy of social context in the review of specific practices and policies and a lexicographical reordering of the responsibilities of medical professionals, including bioethicists, themselves. These changes shift legal and moral responsibility without, hopefully, rejecting the best the field has accomplished.

ACKNOWLEDGEMENT

The author gratefully acknowledges the suggestions of peer reviewers whose comments contributed to the revision of this paper. The comments and attention of Editor, Julian Savulescu, are also gratefully recognised. Similarly acknowledged are the comments of participants at the September 2000 International Bioethics Retreat, Pembroke College, Cambridge University, where an early draft of this work was presented.

This paper stimulated considerable interest in the Olivieri affair. A special symposium will be devoted to this in February 2004. The papers are freely available on the journal's website.

REFERENCES

- 1 Jones AR. The birth of bioethics. *Hastings Cent Rep* 1998;**23**:S5.
- 2 Pellegrino ED. The metamorphosis of medical ethics: a 30 year perspective. *JAMA* 1993;**269**:1158-62.
- 3 Binmore K. *Just playing: game theory and the social contract II*. Cambridge: MIT Press, 1998:511.
- 4 Beauchamp TL, Childress JF. *Principles of biomedical ethics*. [4th ed]. NY: Oxford University Press, 1994.
- 5 Thomasma DC. Bioethics and international human rights. *J Law Med Ethics* 1997;**25**:295-306.
- 6 Koch T. *The limits of principle: deciding who lives and what dies*. Westport, CT, and London: Praeger Books, 1998.
- 7 Lowry EH. Of health care professionals, ethics, and strikes. *Camb Q Healthc Ethics* 2000;**9**:513-20.
- 8 Baylis F. Heroes in bioethics. *Hastings Cent Rep* 2000;**31**:34-9.
- 9 Sandstrom E. Medical agencies fear drop in organ donations. *Beacon Journal (Akron)* 1997 Apr 9:A1.
- 10 Kolata G. Controversy erupts over organ removals. *The New York Times* 1997 Apr 13;Sect 1, 28.
- 11 Agich G. From Pittsburgh to Cleveland: NHBD controversies and bioethics. *Camb Q Healthc Ethics* 1999;**8**:269-74.
- 12 Waithe ME. Blowing the whistle on transplant protocol [letter]. *Cleveland Plain Dealer* 1997 May 21:13.
- 13 National Organ Transplant Act (NOTA). Pub l no 98-507; 98 stat 2339 1984.
- 14 McCurdy DB. Disclosure v confidentiality: When disaster strikes. *Making the Rounds in Health, Faith, & Ethics* 1996;**1**:1-5.
- 15 Spielman B, Verhulst S. Non-heartbeating cadaver procurement and the work of ethics committees. *Camb Q Healthc Ethics* 1997;**6**:282-7.
- 16 Fisher J. Re-examining death: against a higher brain criterion. *J Med Ethics* 1999;**25**:473-6.
- 17 Truog RD. Is it time to abandon brain death? *Hastings Cent Rep* 1997;**17**:27-31.
- 18 Koch T. *Scarce goods: justice, fairness, and organ transplantation*. Westport CT and London: Praeger Publishing, 2002.
- 19 Niewijk A. Tough priorities: organ triage and the legacy of apartheid. *Hastings Cent Rep* 1999;**29**:42-50.
- 20 Sheper-Hughes N. The global traffic in human organs. *Curr Anthropol* 2000;**41**:191-225.
- 21 Mandel M. Nancy and Goliath/sick kids' doctors' battle with drug giant is anything but black and white. *Ottawa Sun* 1998 Dec 7:8.
- 22 Olivieri NF, Brittenham GM, McLaren CE, et al. Long term safety and effectiveness of iron chelation therapy with Deferiprone for thalassaemia major. *N Engl J Med* 1998;**339**:417-23.
- 23 Anon. Drug risk revealed. *Toronto Sun* 1998 Aug 14:50.
- 24 Anon. Researcher strikes back. *Winnipeg Sun* 1998 Dec 11:13.
- 25 Anon. MDs push drug probe. *Winnipeg Sun* 1998 Aug 18:12.
- 26 Chapman D. Hospital admits errors/sick kids: says it backs researcher but. *Toronto Sun* 1998 Dec 11:60.
- 27 Brittenham GM, Fleming KA, Olivieri N. Iron chelation with oral Deferiprone in patients with thalassaemia [letter]. *N Engl J Med* 1998;**339**:1710-14.
- 28 Savulescu J. Harm, ethics committees, and the gene therapy death [editorial]. *J Med Ethics* 2001;**27**:148-50.
- 29 Savulescu J, Spriggs M. The hexamethonium asthma study and the death of a normal volunteer in research. *J Med Ethics* 2002;**28**:3-4.
- 30 Recer P. Accusations in gene therapy death. *Associated Press*, <http://www.dialog.com/APNES> (accessed 2 Feb 2002).
- 31 Elliott C. Pharma buys a conscience. *The American Prospect* 2001 Sept 24. <http://www.prospect.org/print/V12/17/elliott-c.html> (accessed 27 Mar 2002).
- 32 R v Latimer (1994) 124 Saskatchewan R 9, 19-59.
- 33 R v Latimer (1995), 99 CCC (3d) 481.
- 34 R v Latimer [1997] 1 SCR 217.
- 35 Rock M. Discounted lives? Weighing disability when measuring health and ruling on "compassionate" murder. *Soc Sci Med* 2000;**51**:407-17.
- 36 Albright AL, Cervi A, Singletary J. Intrathecal Baclofen for spasticity in cerebral palsy. *JAMA* 1991;**265**:1418-23.
- 37 FDA peripheral and central nervous system drugs advisory committee. Medtronic intrathecal Baclofen receives approval of recommendation for treating refractory spasticity. *FDC Reports Prescription and OTC Pharmaceutical* 1991;**53**:9-11.
- 38 Albright AL, Barron WB, Fasick PM, et al. Continuous intrathecal Baclofen infusion for spasticity of cerebral origin. *JAMA* 1993;**270**:2475-8.
- 39 Koch T, Braun K, Pietsch J. Social necessity, individual rights, and the needs of the fragile: euthanasia in the context of end of life decision making. *J Ethics Law Aging* 1999;**5**:557-60.
- 40 Jonsen A. The birth of bioethics: the origins of a demi-discipline. *Med Humanit Rev* 1997;**2**:9-21.
- 41 Tuner L. Bioethics, public health, and firearm-related violence: missing links between bioethics and public health. *J Law Med Ethics* 1997;**25**:42-8.
- 42 Neuland S. *Doctors: the biography of medicine*. New York: Vintage Books, 1989;ch 11.
- 43 Snow J. *On the mode of the communication of cholera*. [2nd ed]. London: Churchill, 1854.
- 44 Lewontin RC. *Biology as ideology: the doctrine of DNA*. NY: HarperCollins Books, 1993.
- 45 Equality and disability symposium. *J Med Ethics* 2001;**27**:361-92.
- 46 Crisp R, Hope T, Ebbs D. The Asbury draft policy on ethical use of resources. *BMJ* 1996;**312**:1528-33.
- 47 Thomasma DC. Commentary: guidelines for rationing resemble process of family decision making. 1996;**312**:1531-2.
- 48 Wolfe SM. Shifting paradigms in bioethics and health law: the rise of a new pragmatism. *Am J Law Med* 1994;**20**:395-415.