Are medical ethicists out of touch? Practitioner attitudes in the US and UK towards decisions at the end of life

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Abstract

Objectives—To assess whether UK and US health care professionals share the views of medical ethicists about medical futility, withdrawing/withholding treatment, ordinary/extraordinary interventions, and the doctrine of double effect

Design, subjects and setting—A 138-item attitudinal questionnaire completed by 469 UK nurses studying the Open University course on “Death and Dying” was compared with a similar questionnaire administered to 759 US nurses and 687 US doctors taking the Hastings Center course on “Decisions near the End of Life”.

Results—Practitioners accept the relevance of concepts widely disparaged by bioethicists: double effect, medical futility, and the distinctions between heroic/ordinary interventions and withholding/withdrawal of treatment. Within the UK nurses’ group a “rationalist” axis of respondents who describe themselves as having “no religion” are closer to the bioethics consensus on withholding and withdrawing treatment.

Conclusions—Professionals’ beliefs differ substantially from the recommendations of their professional bodies and from majority opinion in bioethics. Bioethicists should be cautious about assuming that their opinions will be readily accepted by practitioners.

Keywords: Death and dying; withdrawal of care; refusal of treatment

Introduction

For the past thirty years bioethicists’ bread-and-butter has been critical examination of faulty thinking in biomedical practice. Where stereotypes and muddle prevailed, we have seen it as our task to bring philosophical clarity. On the face of it this is an admirable task, but some professional reputations have been built on clever hypotheticals with little relation to everyday practice. Furthermore, consequentialist approaches have tended to dominate, particularly in the area of death and dying.

For example, the President’s Commission and other US official recommendations rejected the distinction between withholding and withdrawing treatment because they have the same effect. Similarly, clinicians who believe that there is a distinction (and that withdrawing treatment is more serious) might be less likely to initiate potentially useful treatments which they may later have to withdraw. Both these arguments are drawn from ethical consequentialism. By contrast, other approaches such as narrative ethics, hermeneutics, the ethics of care, or a power model might view withdrawing care as different from withholding it: new relationships and expectations have been built up during the period in which care has been offered.

Likewise, the consensus in biomedical ethics has generally been against the distinction between ordinary and extraordinary treatment. Whereas extraordinary treatment can permissibly be forgone, in Catholic theology, ordinary treatment cannot. As stated by Cardinal Jean Villot, Vatican Secretary of State, in 1970, the same distinction applies to the doctor’s duties as to the patient’s: “A medical man does not have to use all the techniques of survival offered him by a constantly creative science. In many cases, would it not be useless torture to impose vegetative resuscitation in the final stages of an incurable sickness?”

However, what was extraordinary in 1970, when Cardinal Villot made his pronouncement, may now be ordinary. With the fluid boundary between what is technologically extraordinary one day and perfectly standard practice the next, there is some practical basis for scepticism about the distinction, but many writers in bioethics have concentrated on the philosophical incoherence of the contrast instead. Other once-standard distinctions which have come in for “demolition” include that between “active” and “passive” euthanasia and between relieving suffering versus shortening life, as in the doctrine of double effect.

The concept of medical futility has been a particular focus of controversy. Because an underpinning definition of futility is crucial to decisions about withholding or stopping interventions, and because the greatest problem in American practice has often been seen as the tendency towards excessive interventions, futility has been a linchpin concept. Yet bioethicists have been suspicious of futility as merely a rationalisation, or as “too ambiguous and pejorative a term”.

Do doctors and nurses still use the concepts which many bioethicists have done their best to discredit? If so, do they do so out of ignorance, or is there a coherent pattern to their attitudes on decisions in death and dying—evidence, perhaps, of
Methods
For an in-hospital ethics training programme on "Decisions near the end of life", the Hastings Center and the Education Development Center (EDC) developed a questionnaire on practitioners’ attitudes towards ethical issues in death and dying, funded by the Kellogg Foundation. This “institutional profile” was piloted with 72 subjects and reviewed by an external panel of experts in clinical ethics, sociology, anthropology, health services research, psychology and statistics. A repeat survey was administered two months later (n=52). Test reliability was estimated as good, using several different techniques. After this piloting process, the questionnaire was administered at five test hospitals ranging in size from 180 to 660 beds. The total numbers responding were 759 nurses and 687 doctors (369 internists, 174 surgeons, and 144 house officers).

For the Hastings Center, the primary purpose of the questionnaire was to “ground” the work which practitioners would be doing in their six-session training programme, by forcing them to define at the outset their own attitudes, values and ethical beliefs on such issues as withdrawing/withholding. Clinicians and patients (UK: dying people) generally agree about what constitutes medically futile treatment. However, the US and UK nurse groups both encountered the questionnaire very similarly, more so than the US doctors, who were more familiar with UK practice, the questions in the tables below used exactly the same wording, with three very minor exceptions [tables 1, 2 and 9] in which the UK version appears in brackets.

Completion of the questionnaire was optional on a scale of 1 to 5 (1=strongly disagree, 5=strongly agree) to the following questions:

1. The distinction between extraordinary (or heroic) measures and ordinary treatments is helpful in making termination decisions.
2. Clinicians need better guidelines to help determine when treatments are medically futile.
3. Clinicians are not required to provide medically futile treatment, even if a terminally ill patient or family member demands it.
4. Clinicians are not required to provide medically futile treatment, even if a terminally ill patient or family member demands it.

another sort of consensus than the bioethical one. In short, is bioethics in touch with what practitioners really think?

A UK version of the questionnaire was developed by the author for an Open University course on “Death and Dying”, again with both pedagogic and research objectives. Following a pilot run with 43 UK practitioners, the questionnaire was completed by 469 UK hospital and hospice nurses who were students on the Open University course between 1993 and 1997. (Although some questions from the US instrument were eliminated or redrafted to suit UK practice, the questions in the tables below used exactly the same wording, with three very minor exceptions [tables 1, 2 and 9] in which the UK version appears in brackets.)

Completion of the questionnaire was optional on the Open University course, unlike the US counterpart, making numbers somewhat lower. In particular, there were too few doctors for statistical analysis. No UK doctors appear in the findings reported in this article, although findings concerning US doctors have been included for interest, and in some cases, for reporting comparisons between professions in the US.

The UK group includes a larger proportion of hospice nurses than the US sample, and therefore probably a higher exposure to critically or terminally ill patients. However, the US and UK nurse groups both encountered the questionnaire very early in their study, so that untutored responses are being measured. The nurse groups are also broadly comparable in terms of means for age (US=39.5, UK=38.0) and number of years in the nursing profession (US=13.9, UK=15.6).

Although further research is desirable to ascertain UK doctors’ attitudes, UK nurses, of all British practitioner groups, may well give us the best idea of how relevant to terminal care are the concepts of double effect, futility and heroic/ordinary treatment. The US findings showed that nurses had the greatest amount of contact with dying people and surgical attending physicians the least. Nursing ethics, heavily influenced by the ethics of care, might also be particularly reluctant to accept the authority of the biomedical ethics establishment on such questions as withdrawing and withholding.

Table 1 Practitioner acceptance of the concepts of medical futility and extraordinary/ordinary treatments

<table>
<thead>
<tr>
<th>Question</th>
<th>1 strongly disagree</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 strongly agree</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Heroic distinction useful</td>
<td>3% (4%)</td>
<td>8% (7%)</td>
<td>19% (19%)</td>
<td>43% (31%)</td>
<td>26% (39%)</td>
<td>3.80 (3.92)</td>
</tr>
<tr>
<td>2) Futility guidelines needed</td>
<td>1% (4%)</td>
<td>5% (7%)</td>
<td>15% (19%)</td>
<td>38% (32%)</td>
<td>41% (39%)</td>
<td>4.12 (3.94)</td>
</tr>
<tr>
<td>3) Dying agree</td>
<td>23% (18%)</td>
<td>42% (33%)</td>
<td>18% (28%)</td>
<td>13% (17%)</td>
<td>2% (5%)</td>
<td>2.32 (2.57)</td>
</tr>
<tr>
<td>4) Futile treatment not required</td>
<td>5% (26%)</td>
<td>13% (25%)</td>
<td>27% (19%)</td>
<td>37% (14%)</td>
<td>17% (16%)</td>
<td>3.48 (2.67)</td>
</tr>
</tbody>
</table>

Obtaining DNR orders 88% (64%)
Documenting reasons for DNR order 63% (58%)
Requests for organ donation 77% (56%)
Recording patient’s wishes in medical record 69% (72%)
Obtaining informed consent 84% (77%)
Determining patient capacity to participate in decisions 61% (40%)
Withholding or stopping mechanical ventilation 53% (37%)
Withholding or stopping artificial nutrition and hydration 41% (34%)
How to proceed when ethical concerns about a patient’s care arise 61% (46%)
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Table 3  Sources of intra-staff conflict identified by UK nurses

<table>
<thead>
<tr>
<th>Source of conflict</th>
<th>UK nurses</th>
<th>US nurses</th>
<th>US internists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Determination of patients’ capacity to make decisions</td>
<td>2.54</td>
<td>2.45</td>
<td>1.96</td>
</tr>
<tr>
<td>Adequacy of the informed consent process</td>
<td></td>
<td></td>
<td>2.45</td>
</tr>
<tr>
<td>Use of patients in research projects</td>
<td></td>
<td></td>
<td>1.96</td>
</tr>
<tr>
<td>How information is given to patients and families</td>
<td></td>
<td></td>
<td>2.63</td>
</tr>
<tr>
<td>Deciding when a treatment is medically futile</td>
<td></td>
<td></td>
<td>2.70</td>
</tr>
<tr>
<td>What treatment alternative is best for a patient</td>
<td></td>
<td></td>
<td>2.69</td>
</tr>
<tr>
<td>When to consider the economic costs of a patient’s care</td>
<td>2.20</td>
<td></td>
<td>3.88</td>
</tr>
</tbody>
</table>

Table 4  Undertreatment and overtreatment in UK and US practice

<table>
<thead>
<tr>
<th>Statement</th>
<th>UK nurses</th>
<th>US nurses</th>
<th>US internists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment burdensome</td>
<td>3.31 (52%)</td>
<td>3.43 (58%)</td>
<td>3.02 (45%)</td>
</tr>
<tr>
<td>Give up too soon</td>
<td>2.33 (20%)</td>
<td>2.22 (15%)</td>
<td>1.84 (7%)</td>
</tr>
</tbody>
</table>

For items 1 and 2, differences by profession and nationality are significant at p<0.0001 (one-way analysis of variance).
might have the e
prescribe analgesic medication in quantities that
woman dying of motor neurone disease, to
general practitioner's willingness, at the request of a
Lindsell that existing law could accommodate a
High Court clarified in the 1997 case of Annie
it is accepted by many practitioners. In England the
extent that they see an important moral distinction
between stopping treatment and assisting suicide.
Likewise, practitioners largely accept
the distinction between “passive” and “active”
euthanasia, distrusted by many bioethicists, to the
pain relief. Although the consequences of the two actions may
be the same, seven out of eight practitioners
agreed, this judgment confirms what many
practitioners already believe.
Only three per cent of UK nurses disagreed or
strongly disagreed with this statement. The great
majority reject the argument (made by the
Voluntary Euthanasia Society in the 1994 hearings
before the House of Lords Select Committee on
Euthanasia) that it is hypocritical to give analgesics
in the knowledge that the patient’s death may
result, while claiming only to be concerned with
pain relief. Likewise, practitioners largely accept
the distinction between “passive” and “active”
euthanasia, distrusted by many bioethicists, to the
extent that they see an important moral distinction
between stopping treatment and assisting suicide.27
Although the consequences of the two actions may
be the same, seven out of eight practitioners
surveyed, across countries and professions, agree or
strongly agree that the content of the actions is
ethically different (table 7).

3. DOUBLE EFFECT AND EUTHANASIA
Some bioethicists, and most supporters of euthana-
sia, regard the doctrine of double effect as a hypo-
critical remnant of Catholic moral theology28 29, but
it is accepted by many practitioners. In England the
High Court clarified in the 1997 case of Annie
Lindsell that existing law could accommodate a
general practitioner’s willingness, at the request of a
woman dying of motor neurone disease, to
prescribe analgesic medication in quantities that
might have the effect of shortening her life. As table
6 indicates, this judgment confirms what many
practitioners already believe.

| Table 5 | Is withdrawing treatment ethically different from never starting it?
| Percentage agreeing or strongly agreeing with the statement "There is no ethical difference between withholding (not starting) a life support measure and stopping it once it has been started", with mean score (in parentheses), on scale of 1 to 5 (1=strongly disagree, 5=strongly agree) |
| 20% (2.39) | 43% (3.00) | 38% (2.84) | 44% (2.96) | 27% (2.49) | 34% (2.71) |

| Table 6 | Practitioner agreement with the doctrine of double effect
| Percentage agreeing or strongly agreeing with the statement: “Sometimes it is appropriate to give pain medication to relieve suffering, even if it may hasten a patient’s death” with mean score (in parentheses), on scale of 1 to 5 (1=strongly disagree, 5=strongly agree) |
| 94% (4.67) | 94% (4.55) | 92% (4.52) | 92% (4.56) | 86% (4.35) | 89% (4.44) |

4. PATIENT PARTICIPATION AND PRACTITIONER SATISFACTION
On attitudes towards patient autonomy and partici-
pation in decision making, UK nurses demonstrate
a greater commitment than any of the US groups,
as shown in table 9, particularly questions 1 and 2.
(Note that a high score on question 1 indicates
strong commitment to letting the patient decide,

Table 7 | Practitioner agreement with distinction between withholding treatment and assisting suicide
| Percentage agreeing or strongly agreeing with the statement: “To allow patients to die by forgoing or stopping treatment is ethically different from assisting in their suicide”, with mean score (in parentheses), on scale of 1 to 5 (1=strongly disagree, 5=strongly agree) |
| 87% (4.22) | 89% (4.47) | 86% (4.44) | 94% (4.57) | 85% (4.33) | 87% (4.41) |

Table 8 | Practitioner agreement with the statement: “Disconnecting a feeding tube is killing a patient”
| Percentage agreeing or strongly agreeing with statement, on scale of 1=strongly disagree, 5=strongly agree, with mean score in parentheses. |
| 18% (2.22) | 11% (1.84) | 12% (1.89) | 9% (1.62) | 12% (1.97) | 12% (1.89) |
5. RATIONALISM, RELIGION AND ATTITUDES

Towards National Guidelines

A substantial number of UK nurses surveyed describe themselves as having “no religion”. This group, whom I call “rationalists”, shows a statistically significant degree of scepticism about the distinction between withholding and withdrawing treatment, but not about the doctrine of double effect concerning unintentionally hastening death (table 11). Although double effect is originally a Catholic doctrine, UK nurses of all religions, and of no religion, accept it. In fact practitioners who have no religion actually accept it slightly more strongly and more consistently (having a lower standard deviation). This is probably because they have fewer qualms about intentionally hastening death than the other two groups. On the other two questions, the “rationalist” minority does hold views which are significantly different. They are far more likely to agree (with the professional bodies’ consensus) that there is no difference between withdrawing treatment once started and not offering it in the first place. And they are much more sympathetic to assisted suicide, a difference significant at the .0001 level.

This table offers us a suggestive answer to the question of why practitioners’ attitudes are intractable to persuasion by national recommendations: these attitudes could correlate with religious belief—or lack of it. Academic ethicists are likely to be rationalists themselves; others like Tristram Engelhardt, himself an active church member, are concerned to develop a common core of principles on which believers and non-believers could all agree.” Does the secular orientation of modern bioethics help to account for the distance between the bioethical consensus and practitioners’ beliefs?

Conclusions

Whether practitioners do accept doctrines and concepts widely disparaged by bioethicists says nothing, of course, about whether they should accept them. To argue otherwise is to fall prey to the naturalistic fallacy.” Solomon et al generally assumed that practitioners should not distinguish between withdrawing and withholding care, in the face of national commission recommendations to

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positivism and her colleagues often appear to accept scientific guidelines, that does not explain all the disparity they are ethically ignorant. Although practitioners do not. If they disagree with national recommendations, that does not necessarily mean that they are ethically ignorant. Although practitioners do show a degree of ignorance of national guidelines, that does not explain all the disparity between their beliefs and the bioethics consensus. Perhaps, to paraphrase Thoreau, they simply march to the beat of a different drummer.

We need to know more about why practitioners differ from bioethicists, and from each other, in their attitudes towards decisions near the end of life. These findings are preliminary: further research is required to ascertain levels of significance for comparisons between US and UK practitioners, and to measure the attitudes of UK doctors. Yet wanting to know more is an important first step: it implies that practitioners’ attitudes are not merely misguided, but may reflect alternative and equally valid models. One such alternative model of medical ethics is rooted in phronesis, the Aristotelian concept of the skills of practical judgment. We would expect practitioners to have particular skills in practical judgment, and to have something to teach us. Whether or not we bioethicists want to accept that particular model, we should at least be sensitive to the possibility that we are indeed out of touch.

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References and notes
3 See, for example: Stanley JM, ed. The Appleton consensus: suggested international guidelines for decisions to forgo medical treatment. Appleton, Wisconsin: Lawrence University, 1992 and
tors always felt an obligation to continue with treatment once
initiated, even if the patient changed her mind.
4 Rosenstand N. The moral of the story: an introduction to ethics
[2nd ed]. Mountain View, California: Mayfield Publishing,
1997.
5 Levine P. Living without philosophy: on narrative, rhetoric and
281–6.
6 Widdershoven G. Discussing cases in clinical ethics: ethical
problem-solving, moral phenomenology or hermeneutic dis-
narrative. In: Josselson R, ed. The narrative study of lives. Thou-
7 Newnham R. Narrative ethics. Cambridge, Massachusetts: Har-
8 Widdershoven G. Discussing cases in clinical ethics: ethical
problem-solving, moral phenomenology or hermeneutic dia-
logue. Bulletin of the European Society for Philosophy of Medicine
narrative. In: Josselson R, ed. The narrative study of lives. Thou-
9 Noddings N. Caring: a feminine approach to ethics and moral edu-
Feminist morality: transforming culture, society and politics
Chicago: University of Chicago Press, 1993. Bowden P. Caring:
10 Brody HA. The healer’s power. New Haven: Yale University
11 Gillon R. Philosophical medical ethics. Chichester: John Wiley,
12 Cited in Maguire DC. A Catholic view of mercy killing. In:
Kohli M, ed. Beneficent euthanasia. Buffalo, New York:
Prometheus Books, 1975: 75.
13 Brock DW. Death and dying. In: Life and death: philosophical
essays in biomedical ethics. Cambridge: Cambridge University
14 Rachels J. A. The end of life: euthanasia and morality. Oxford:
15 Glover J. Caring death and saving lives. Harmondsworth: Pen-
16 Among many other sources, see: Journal of Medicine and Philos-
phy 1995;20:2. Zucker MB, Zucker HD, eds. Medical futility at the
end of life-sustaining interventions. Cambridge: Cambridge University
effective medical care: ethical analysis of issues in cardiopul-
monary resuscitation (CPR). Journal of Medical Ethics
17 Gillon R. Futility and medical ethics [editorial]. Journal of
Medical Ethics 1997;23: 339-40.
18 O’Donnell L, et al. Provider satisfaction with treatment
decisions near the end of life. Health Services Research 1992;22:
340–51.
19 Solomon MZ, O’Donnell L, Jennings B, Guilfoy V, Wolf SM,
Nolan K. Decisions near the end of life: professional views on
life-sustaining treatments. American Journal of Public Health
1993;83:14-23.
London: Routledge, 1994. Allmark P. Can there be an ethics of
Yes! There is an ethics of care: an answer for Peter Allmark.
23 Gundersen R. Medicine and the pursuit of wealth. Hastings
24 Daniels N, Sabin JE. Last chance therapies and managed care.
25 Institute of Medical Ethics Working Party on the Ethics of Pro-
26 Kuhse H, Singer P. Should the baby live? The problem of
27 Hopkins PD. Why does removing machines count as “passive”
29 Dickenson D. Practitioners’ attitudes towards ethical issues at
the end of life: is the UK actually more autonomy-minded than
30 In sense (3) as used by Flew: The rejection of religious belief as being without rational foundation. In: Flew A, ed. A dictionary of
31 Engelhardt T. The foundations of bioethics. Oxford: Oxford Uni-
32 “The mistake … of deducing conclusions about what ought to
be from premises that state only what is the case: or the other
way about”. First labelled by G E Moore in Principia ethica,
1903, edited by Thomas Baldwin. Cambridge: Cambridge
33 See reference 19: 15.
34 Halfpenny P. Positivism. In: Miller D, Coleman J, Connelly W,
35 Hope T. Empirical medical ethics. Journal of Medical Ethics