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 withdrawing/withholding 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 ordinary in 1970, when Cardinal Villot made his pronouncement, may now be extraordinary. 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
another sort of consensus than the bioethical one. In short, is bioethics in touch with what practitioners really think?

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 treatment, artificial hydration and nutrition, and cardiopulmonary resuscitation. For the EDC the prime interest was in compiling an expanding database reflecting current US practitioner attitudes towards issues around assisting death and letting die.11

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.

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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>

Table 2: Awareness of Guidelines

<table>
<thead>
<tr>
<th>Percentage replying “yes” to the question: Are you aware of any guidelines at your institution about the following: (US overall figures, with UK nurses in brackets)</th>
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<tbody>
<tr>
<td>Obtaining DNR orders</td>
</tr>
<tr>
<td>Documenting reasons for DNR order</td>
</tr>
<tr>
<td>Requests for organ donation</td>
</tr>
<tr>
<td>Recording patient’s wishes in medical record</td>
</tr>
<tr>
<td>Obtaining informed consent</td>
</tr>
<tr>
<td>Determining patient capacity to participate in decisions</td>
</tr>
<tr>
<td>Withholding or stopping mechanical ventilation</td>
</tr>
<tr>
<td>Withholding or stopping artificial nutrition and hydration</td>
</tr>
<tr>
<td>How to proceed when ethical concerns about a patient’s care arise</td>
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further research is necessary to determine the level of significance). This finding contrasts with practitioners’ agreement on the “utility of futility”: what to do once a treatment has been identified as futile is another matter. The American majority agree or strongly agree that medically futile treatment is not obligatory even if patients or their families disagree. In contrast, 54 per cent of UK nurses agree or strongly agree that medically futile treatment is not obligatory even if patients and families disagree. (English law is generally loath to require doctors to act against their clinical judgment in providing futile treatment.) United Kingdom nurses, however, report that futility causes more discord among clinical teams in the UK than any other issue, even expensive cardiopulmonary resuscitation (table 3).

Table 3 Sources of intra-staff conflict identified by UK nurses

<table>
<thead>
<tr>
<th>How often do disagreements among staff arise over the following?</th>
<th>(1=almost never, 5=almost always) (mean and percentage answering either 3, 4 or 5)</th>
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<tbody>
<tr>
<td>Determination of patients’ capacity to make decisions</td>
<td>2.54 (51.4%)</td>
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<tr>
<td>Adequacy of the informed consent process</td>
<td>2.45 (48.8%)</td>
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<tr>
<td>Use of patients in research projects</td>
<td>1.96 (30.9%)</td>
</tr>
<tr>
<td>How information is given to patients and families</td>
<td>2.63 (55.6%)</td>
</tr>
<tr>
<td>Deciding when a treatment is medically futile</td>
<td>2.70 (60.3%)</td>
</tr>
<tr>
<td>What treatment alternative is best for a patient</td>
<td>2.69 (58.4%)</td>
</tr>
<tr>
<td>When to consider the economic costs of a patient’s care</td>
<td>2.20 (38.8%)</td>
</tr>
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Results and discussion

1. MEDICAL FUTILITY AND EXTRAORDINARY TREATMENT

Question 1 of table 1 shows 69 per cent (UK nurses) and 70 per cent (US overall) agreeing or strongly agreeing that the distinction between extraordinary and ordinary treatment measures is useful, with 11 per cent in both countries disagreeing. (In fact this agreement prevails across all US professional groups: medical attending physicians mean 3.88, surgical attending 4.06, house officers 3.89 and nurses 4.02.) Consistent with this distinction, which implies that extraordinary measures are not required because they impose disproportionate burdens with minimal results, clinicians in both countries favor stronger guidelines on medical futility from professional bodies. (The survey was administered before the British Medical Association [BMA] guidelines on withdrawing and withholding treatment were published in September 1999.) This result on question 2, table 1, is interesting because awareness of existing guidelines is reasonably high in both national groups—although consistently higher in the UK (table 2).

Item 3 of table 1 shows that 65 and 61 per cent of UK nurses (UK and US respectively) disagree or disagree strongly with the statement that “Clinicians and dying people generally agree about what constitutes medically futile treatment”. Only two and five per cent, respectively, strongly agree that they normally reach an accord with dying people and their families over whether to continue aggressive interventions. In question 4 of table 1, US and UK practitioners disagree sharply over whether clinicians must provide medically futile treatment if dying people and their families demand it (although...
might have the e

guidelines of September 1999 (see references 2 and 3 for US).

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 theology \[23, 26\], 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
woman dying of motor neurone disease, to
prescribe analgesic medication in quantities that
might have the effect of shortening her life. As table
indicates, 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).

Junior doctors in the US are most likely to agree
with this statement, and US nurses most likely to
disagree, although only 11 per cent of the latter
disagreed or strongly disagreed with the statement.
It is often said that nurses are more unwilling to see
treatment stopped than doctors, because they are
more intimately involved in patient care. In the case
of the persistent vegetative state (PVS) patient Tony
Bland, for example, nurses initially opposed the
decision by the family and consultant to withdraw
artificial nutrition and hydration.\[28\] But both nurses
and doctors surveyed reject the argument that
because the consequences of treatment withdrawal
and assisted suicide are the same, there is no ethical
distinction. When the question of disconnecting
feeding tubes is tackled more explicitly, a slightly
diminished majority of practitioners still uphold the
distinction between that and euthanasia, as table 8
indicates.

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 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).

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<tr>
<td>20% (2.39)</td>
<td>43% (3.00)</td>
<td>38% (2.84)</td>
<td>44% (2.96)</td>
<td>27% (2.49)</td>
<td>34% (2.71)</td>
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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).

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<tr>
<td>94% (4.67)</td>
<td>94% (4.55)</td>
<td>92% (4.52)</td>
<td>92% (4.56)</td>
<td>86% (4.35)</td>
<td>89% (4.44)</td>
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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).

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<td>87% (4.22)</td>
<td>89% (4.47)</td>
<td>86% (4.44)</td>
<td>94% (4.57)</td>
<td>85% (4.33)</td>
<td>87% (4.41)</td>
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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.

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<tr>
<td>18% (2.22)</td>
<td>11% (1.84)</td>
<td>12% (1.89)</td>
<td>9% (1.62)</td>
<td>12% (1.97)</td>
<td>12% (1.89)</td>
</tr>
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</table>
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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the contrary. If implemented, Solomon et al felt, the official bodies’ directives would undermine the “technological imperative” of overtreatment and aggressive intervention at the end of life. But even though US practitioners generally agreed that dying patients were more likely to be overtreated than abandoned too soon, they had not accepted the corollary attitudes that would weaken the grip of the technological imperative. For example, they were loath to withdraw care once started, because they felt that stopping treatment was more serious than withholding it in the first place.

One solution proposed by Solomon et al was that bioethicists should step up their efforts to educate practitioners about national guidelines. Solomon and her colleagues often appear to accept scientific positivism: bioethics comes across as an activity in which specialists make scientifically validated advances and practitioners accept them. I want to argue the other way around: practitioners can educate us, and empirical evidence about what they really think can add maturing sophistication to the traditional analytical concerns of bioethics. Medical ethics risks becoming a self-regarding activity if it does not incorporate what practitioners think and do. This is certainly not to say that we should slavishly follow practitioner opinion when we know it to be fuzzy thinking; but neither should we condemn practitioner opinion as misguided. Nor should we try to reduce medical ethics to a positivistic model which we, in our wisdom, can then hand on to clinicians.

Medical ethicists who espouse an a priori model of decision making, such as principlists, are more likely to think that practitioners are just plain wrong if they persist in opinions which contradict the collective wisdom of bioethicists. If ethical decision making is a matter of coherent a priori reasoning, then there is no reason to expect practitioners to excel at what they were never trained to do, and every reason to believe that philosophers will make a better job of it. Conversely, if the facts of actual cases make a difference, and if an empirical model of decision making is preferred, then practitioners can be expected to know something which philosophers do not. But 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.

Acknowledgements

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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 treat-ment. Appleton, Wisconsin: Lawrence University, 1992 and
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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 University Press, 1994. See also: reference 30: 223.

33. See reference 19: 15.


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