



Universiteit
Leiden
The Netherlands

Clinical ethical dilemmas: convergent and divergent views of two scholarly communities

Stiggelbout, A.M.; Elstein, A.S.; Molewijk, B.; Otten, W.; Kievit, J.

Citation

Stiggelbout, A. M., Elstein, A. S., Molewijk, B., Otten, W., & Kievit, J. (2006). Clinical ethical dilemmas: convergent and divergent views of two scholarly communities. *Journal Of Medical Ethics*, 32, 381-388. Retrieved from <https://hdl.handle.net/1887/8777>

Version: Not Applicable (or Unknown)

License:

Downloaded from: <https://hdl.handle.net/1887/8777>

Note: To cite this publication please use the final published version (if applicable).



Clinical ethical dilemmas: convergent and divergent views of two scholarly communities

A M Stiggelbout, A S Elstein, B Molewijk, W Otten and J Kievit

J. Med. Ethics 2006;32:381-388
doi:10.1136/jme.2005.011791

Updated information and services can be found at:
<http://jme.bmjournals.com/cgi/content/full/32/7/381>

These include:

Data supplement

"Web-only appendix"
<http://jme.bmjournals.com/cgi/content/full/32/7/381/DC1>

References

This article cites 11 articles, 3 of which can be accessed free at:
<http://jme.bmjournals.com/cgi/content/full/32/7/381#BIBL>

Rapid responses

You can respond to this article at:
<http://jme.bmjournals.com/cgi/eletter-submit/32/7/381>

Email alerting service

Receive free email alerts when new articles cite this article - sign up in the box at the top right corner of the article

Notes

To order reprints of this article go to:
<http://www.bmjournals.com/cgi/reprintform>

To subscribe to *Journal of Medical Ethics* go to:
<http://www.bmjournals.com/subscriptions/>

CLINICAL ETHICS

Clinical ethical dilemmas: convergent and divergent views of two scholarly communities

A M Stiggelbout, A S Elstein, B Molewijk, W Otten, J Kievit

J Med Ethics 2006;32:381–388. doi: 10.1136/jme.2005.011791



Additional material can be viewed online at <http://jme.bmjournals.com/supplemental>

See end of article for authors' affiliations

Correspondence to:
Dr Anne M Stiggelbout,
Department of Medical
Decision Making, Leiden
University Medical Center,
P O Box 9600, 2300 RC
Leiden, The Netherlands;
a.m.stiggelbout@lumc.nl

Received 28 January 2005
In revised form
30 September 2005
Accepted for publication
3 October 2005

Objective: To survey members of the American Society for Bioethics and Humanities (ASBH; $n = 327$) and of the Society for Medical Decision Making (SMDM; $n = 77$) to elicit the similarities and differences in their reasoning about two clinical cases that involved ethical dilemmas.

Cases: Case 1 was that of a patient refusing treatment that a surgeon thought would be beneficial. Case 2 dealt with end-of-life care. The argument was whether intensive treatment should be continued of an unconscious patient with multiorgan failure.

Method: Four questions, with structured multiple alternatives, were asked about each case: identified core problems, needed additional information, appropriate next steps and who the decision maker should be.

Observations and results: Substantial similarities were noticed between the two groups in identifying the core problems, the information needed and the appropriate next steps. SMDM members gave more weight to outcomes and trade-offs and ASBH members had patient autonomy trump other considerations more strongly. In case 1, more than 60% of ASBH respondents identified the patient alone as the decision maker, whereas members of SMDM were almost evenly divided between having the patient as the solo decision maker or preferring a group of some sort as the decision maker, a significant difference ($p < 0.02$). In case 2, both groups agreed that the question of discontinuing treatment should be discussed with the family and that the family alone should not be the decision maker.

Conclusion: Despite distinctively different methods of case analysis and little communication between the two professional communities, many similarities were observed in the actual decisions they reached on the two clinical dilemmas.

Some clinical decisions are difficult for various reasons. There may be a lack of evidence or conflicting evidence. The choices may involve uncertainty about how possible outcomes should be valued and by whom, or conflicting values, such as prolonging life versus quality of life. The outcomes may include a complex mix of benefits and harms, so that the trade-offs are difficult to resolve, even if we are clear about our own values. Such decisions may be characterised as clinical dilemmas, for there are at least two options in the choice set and it is not clear which is preferable and according to which criteria.

Bioethicists and researchers in medical decision making pursue investigations of the reasoning on difficult cases. Both groups are concerned with the prescriptive and descriptive study of decision making. In general, the medical decision-making community uses utilitarianism as the normative paradigm, aiming to maximise the overall good for most people or for a single patient. Bioethicists use various normative paradigms, including virtue ethics, utilitarianism, ethics of care and deontology.¹

Despite their common concerns, there is little communication between the medical decision-making community and the bioethicists. We examined the citation lists of all articles published in 2001 and 2002 in selected core journals in the relevant fields—*Health Economics*; *Medical Care*; and *Medical Decision Making* for medical decision making and *Bioethics*; *Hastings Center Report*; *Journal of Law, Medicine and Ethics*; and *Journal of Medical Ethics* for bioethics. Out of hundreds of citations, fewer than 10 from each group of journals were found in papers published in the other, despite frequent calls for more interdisciplinary cooperation between the social sciences and bioethics.^{2–8}

Differences between the fields may affect their conclusions about specific clinical dilemmas:

1. *Roots and vocabulary:* The origins of clinical bioethics are in philosophy, theology and the humanities,^{9–10} whereas the foundations of medical decision making lie in economics, psychology and decision theory.^{11–13}
2. *Key concepts:* Some bioethicists typically consider the rights, duties and obligations of the various parties. The principle-based approach was dominant in the past decades,¹ but recently other approaches such as care-ethics have become prominent.^{14–15} The medical decision-making community considers clinical dilemmas by systematically identifying the alternatives, and assessing the probability and value of the outcomes in calculating expected utility.
3. *Methods of case analysis:* The medical decision-making community favours decision analysis to explore the relevant issues.¹⁶ Trade-offs are to be made explicit and preferably assessed quantitatively (calculated rationality). For bioethicists, the analysis of issues is narrative and qualitative, not mathematically formal and quantitative.¹⁷

It is generally agreed that competent, well-informed adults have the right to refuse treatment. The situation becomes more problematic for health professionals when refusal can lead to near-term serious harm. In this situation, a clinical dilemma may arise, in the form of a conflict between the

Abbreviations: ASBH, American Society for Bioethics and Humanities; ICU, intensive care unit; SMDM, Society for Medical Decision Making

principles of respect for autonomy and beneficence.¹⁷ We use one case to explore attitudes towards this dilemma.

Another dilemma may arise in end-of-life care around the question of when it is appropriate to discontinue vigorous treatment. Some recent studies have explored the attitudes of health professionals and laypeople towards end-of-life care. Investigators in France¹⁸ asked 221 laypeople and 189 professionals to judge the acceptability of euthanasia in 72 brief clinical scenarios in which levels of life expectancy, patient's request and family attitude varied systematically. The attitudinal structure of both groups was similar. The health professionals included doctors, nurses, psychologists and nurses' aides, and their attitudinal clusters were similar to the lay group and across professions. A study using similar methods¹⁹ explored factors affecting the acceptability of relatively active (injecting a toxin) against relatively passive (disconnecting life support), and voluntary against involuntary euthanasia among laypeople and health professionals, including nurses' aides, nurses and doctors. Again, lay and professional responses were on the whole quite similar, although nurses' aides were closer to the lay group than were the nurses. The sample of doctors was too small to permit statistical comparisons with the other groups, and variation within each professional group was not systematically related to their ethical philosophy.

Some studies have explored attitudinal differences between professional groups or as a function of clinical experience. Solomon *et al*²⁰ surveyed several hundred doctors and nurses in five hospitals. The respondents were not asked about their preferences or choices in specific cases, but were asked to assess more general attitudes, such as whether they believed that they had sometimes acted contrary to conscience in providing care or whether the treatment offered was more of a burden than a benefit to the patient. House officers endorsed these statements more often than attending doctors or nurses, whose attitudes were relatively similar, suggesting a possible effect of experience. Again, differences and similarities in ethical philosophy or outlook were not dealt with in this study.

A search for studies that systematically explored differences in the thinking of the bioethics and decision-making communities yielded only one study: Ubel *et al*²¹ investigated the conflict between the principles of fairness and cost effectiveness in public health decision making among members of the American Association of Bioethics and of the Society for Medical Decision Making (SMDM). Results showed that a slight majority of bioethicists placed equity over cost effectiveness, whereas a similar majority of the SMDM respondents valued cost effectiveness over equity. The results may suggest substantial similarity in the reasoning of the two groups, notwithstanding the evident lack of scholarly communication as reflected in the lack of cross-disciplinary citation. This result, however, may apply specifically to public health dilemmas and not to reasoning about clinical dilemmas.

To examine in more detail the similarities and differences between the two communities with respect to clinical dilemmas, we surveyed the membership of the American Society for Bioethics and Humanities (ASBH) and the SMDM. The aim was to describe their responses to two clinical dilemmas. The choice of the cases and the information we presented for each case were such that the resolution of the dilemma was not obvious beforehand, so that the responses to the cases could be sensitive to the theoretical background of the respondent. We hypothesised that decision makers would focus more on assessing the quality of outcomes, using a utilitarian rationale. For ethicists we had less clear-cut hypotheses, but expected both deontological notions (eg, beneficence *v* patient autonomy) and care-ethical principles to be reflected in the answers. Insights

obtained may facilitate communication between these groups and increase the mutual understanding of and respect for each other's characteristic modes of thinking and deciding.

METHODS

Materials

The survey used two clinical dilemma cases, both actual cases from the Leiden University Medical Center, Leiden, The Netherlands. The first case is that of an elderly man with an asymptomatic aortic aneurysm who prefers watchful waiting to surgery despite the recommendation of his surgeon (see appendix for case description). The second case is that of an elderly man who develops multiorgan failure in the cardiac care unit after major surgery. He is unconscious and has left no living will or advance directive. The team at the intensive care unit (ICU) and hospital administration favour discontinuing active treatment, implying that the patient will be moved from the ICU to make room for another. The patient's wife and children want to continue active treatment. The two cases were chosen because they exemplify moral differences regarding at least two points. Firstly, case 1 focuses at an individual level on a conflict between respect for autonomy and the doctor's obligation to benefit the patient, whereas case 2 embodies a conflict about social justice caused by scarce resources and possibly influenced by futility arguments. Secondly, case 1 deals with the issue to what degree a professional should refrain from doing what he considers beneficial, whereas case 2 embodies two conflicts: (a) between family and professionals about whether to withdraw treatment and (b) among professionals about allocation of a scarce resource (as to which patient should get the ICU bed). Case 2 thus deals with the question to what degree and for what reasons professionals should consent to do something that they consider wrong.

Four questions were asked about each case, each with structured alternatives. The alternatives were developed from a pilot study of the cases, conducted in an interdisciplinary seminar at the Leiden University Medical Center. The seminar, which discussed the two cases in one 3-h session, was run as a focus group consisting of experts in medical decision making and in bioethics. The alternatives were developed from qualitative analysis of a verbatim transcript of this discussion. The description of the cases is in the appendix. The data tables have the alternatives.

The four questions were as follows:

1. Identify and rank the core problem(s) in the case
2. Rank the importance of potential additional information
3. Rank a set of potential appropriate actions
4. Identify the appropriate decision maker.

For the first three questions, respondents were asked to rank as many of the alternatives as they thought were appropriate. They could also add alternatives in a final open question. The fourth question required a single choice from a set of options that included the option "other".

The questionnaire was to be answered anonymously. The institutional review boards at the University of Chicago at Illinois, Illinois, USA, and the Leiden University Medical Center, Leiden, The Netherlands, reviewed and approved the study.

Participants

The survey was distributed to about 350 attendees at the October 2001 meeting of SMDM. It was mailed in June 2002 to about 1500 members of ASBH, with a stamped envelope addressed to one of the investigators. As the respondents were guaranteed anonymity, follow-up of non-respondents was not possible.

Table 1 Medians of alternative formulations of the core problem in case 1

Group	SMDM (n = 76)	ASBH (n = 304)	p, Mann-Whitney test	p, χ^2 test
Patient's preference for short-term survival over long-term life expectancy	5 (41)	5 (23)	NS	0.001
Patient is not sufficiently informed	0 (4)	0 (3)	NS	NS
Patient does not understand the information provided	0 (3)	0 (2)	NS	NS
Controversy about aims or objectives (life expectancy versus quality of life)	7 (57)	7 (62)	NS	NS
Conflict between respect for patient's autonomy and rational choice	4.5 (18)	4 (20)	NS	NS
Conflict between surgeon's wish to do good and respect for patient's autonomy	7 (53)	7 (71)	0.008	0.002
For the individual, statistics are irrelevant	0 (3)	0 (5)	NS	NS

ASBH, American Society for Bioethics and Humanities; SMDM, Society for Medical Decision Making. Values in parentheses are proportions assigning the top two ranks. NS, not significant.

Analysis plan

Ranks were reversed before analysis, so that 8 = high (for a question with 8 alternatives). If for a particular question respondents ranked some alternatives on the list and left the others blank, we assumed the blank ones to be zeros and included these in the analysis. If a respondent did not rank any of the alternatives for a particular question, they were considered to be missing. For questions 1–3, the medians of each alternative were calculated for the two groups. The distributions were typically non-normal, so differences in location between the groups were assessed by the Mann-Whitney tests. We also show the proportion of respondents in each group assigning the highest two ranks (1 or 2 for the unrecoded ranking) and test these proportions using χ^2 tests. Significance was set at $p = 0.01$ because of multiple comparisons. For the fourth question (Who should be the decision maker?), many combinations of decision makers were proposed and each drew too few respondents for a meaningful analysis to be carried out. We collapsed the response categories to two: for case 1, one for the patient alone and the other for all combinations of responses, including the patient and another person or group; for case 2, one for the family and the other for all combinations of responses.

RESULTS

Response rate

In all, 77 responses from SMDM and 327 from ASBH were received (both response rates 22%). A few respondents did not rank all questions, so there is some variation between groups in the range of rankings. For each question (1–3), we analysed those data that did not have missing values for that

particular question to allow for comparison among alternatives (listwise analysis).

Demographics

Respondents were asked to indicate if they were members of SMDM or ASBH or both. No respondent was a member of both societies. The highest earned degree was a doctorate (MD, PhD or DSc) for 79% of ASBH respondents (36% MD, 40% PhD, 3% both) and for 85% of SMDM respondents (45% MD, 33% PhD, 6% both). Differences were not statistically significant.

Case 1

“What is the core problem in this case?” Table 1 shows the medians of the alternatives, as well as the proportion in each group assigning the highest or second highest rank to each alternative. The groups agreed that the two top-ranked core problems are (1) the conflict between beneficence and autonomy and (2) controversy about aims of care. The mean rank assigned by ASBH members to the beneficence or autonomy conflict was significantly higher ($p = 0.008$), as was the proportion ranking this as 1 or 2. Further, a larger proportion of SMDM members ranked the patient's preference for short-term survival over long-term life expectancy as most important ($p = 0.001$).

The second question identified the importance of additional information (table 2). The groups agreed that the most important additional information would be about the patient's values and considerations. Beyond that, they disagreed frequently. SMDM members next ranked the effects on quality of life of both ruptured aneurysm and surgery, whereas ASBH members next ranked the assessment

Table 2 Medians of potential additional information in case 1

Group	SMDM (n = 76)	ASBH (n = 309)	p, Mann-Whitney test	p, χ^2 test
Patient's values and considerations	8 (68)	7 (72)	NS	NS
Both patient's and surgeon's values and considerations	2 (9)	4 (22)	0	0.006
Information on the decision-making process between the patient and the surgeon	4 (11)	5 (28)	0	0.001
Assessment of the patient's competence	5 (24)	6 (34)	NS	NS
Extent of the patients' freedom to make his own decisions	4 (22)	5 (21)	NS	NS
Effects on quality of life of both ruptured aneurysm and surgery	6 (38)	4 (18)	0	0.00
Chances of surgical complications	5 (25)	3 (9)	0	0.00

ASBH, American Society for Bioethics and Humanities; SMDM, Society for Medical Decision Making. Values in parentheses are proportions assigning the top two ranks. NS, not significant.

Table 3 Medians of the potential next steps in case 1

Group	SMDM (n = 77)	ASBH (n = 308)	p, Mann- Whitney test	p, χ^2 test
Interrogate and understand the considerations and values of the patient to decide whether his decision is consistent with his considerations	8 (79)	8 (75)	NS	NS
Suggest patients should reconsider his choice (try to convince with life expectancy information)	0 (8)	0 (8)	NS	NS
Accept the patient's choice and explicitly approve it	0 (17)	0 (16)	NS	NS
Accept the patient's choice even if you disagree with it, but do not explicitly state this	3 (13)	4 (21)	NS	NS
Accept the patient's choice but explicitly state that you disagree with it	2 (18)	0 (16)	NS	NS
Re-evaluate the problem with the surgeon and patient	5 (22)	5 (23)	NS	NS
Try to convince the surgeon that not maximising life expectancy may be a rational and competent decision (if the patient understands all information)	6 (38)	6 (34)	NS	NS

ASBH, American Society for Bioethics and Humanities; SMDM, Society for Medical Decision Making. Values in parentheses are proportions assigning the top two ranks. NS, not significant.

of patient's competence. The ASBH group placed considerably more emphasis on obtaining additional information on the values of both the patient and the surgeon and the decision-making process. The SMDM group ranked higher obtaining information on the chances of surgical complications.

Table 3 shows the appropriate next steps to be considered. Both groups ranked first exploring the considerations and values of the patients to decide whether his decisions is consistent with those values. They also agreed that it would be worthwhile to try to convince the surgeon that not maximising life expectancy may be a rational, competent decision.

"Who should be the decision maker in this case?" Of ASBH respondents, 63% identified the patient alone as the decision maker (see tables provided online at <http://www.jmejournal.com/supplemental>), whereas for members of SMDM this figure was 48% ($\chi^2 = 5.7$, $df = 1$, $p < 0.02$).

Case 2

"What is the core problem in this case?" By wide margins, the groups agree that the leading problems in this case are that it is unclear what is best for the patient, and the view that as further treatment is probably futile it would be inappropriate to continue to treat vigorously (table 4). Only

15–20% in either group endorsed the alternative that the case revolves around the conflict between individual and societal perspectives or that treatment should continue as long as the patient's representative wants.

The two groups agreed that the most needed additional information related to the preferences of the patient or his family, and to his current and future quality of life (table 5). The only significant difference was found for the ranking of guidelines about futile treatment, which ASBH respondents ranked marginally higher than SMDM (and not statistically significant by χ^2). Nevertheless, the medians and proportion ranking this as the top two were quite similar and the groups shared concern about defining futile treatment as the basis for recommending discontinuation of treatment.

Table 6 shows medians for the appropriate next step. The two groups agreed on the top-ranked step, to explain to the family that further treatment is futile and to seek their consent to stop. There was also fair agreement that it was appropriate to follow the family's wishes (ranked second by SMDM and third by ASBH, although a larger proportion of SMDM members ranked this at the top). The groups disagreed about three alternatives that concerned the weight that should be given to the competing interests of the two patients, one already in the ICU and the other waiting for a

Table 4 Medians of alternative formulations of the core problem in case 2

Group	SMDM (n = 76)	ASBH (n = 306)	p, Mann- Whitney test	p, χ^2 test
Considering scarce resources, further vigorous treatment is inappropriate	4 (8)	0 (8)	NS	NS
Considering that further treatment is very likely futile, further vigorous treatment is inappropriate	8 (42)	8 (47)	NS	NS
Conflict between patient perspective and societal perspective	6 (21)	6 (16)	NS	NS
Lack of a hospital or governmental policy for allocating ICU beds	0 (8)	0 (6)	NS	NS
A patient in an ICU bed has a stronger moral right to treatment than someone on a waiting list, regardless of health status	0 (1)	0 (3)	NS	NS
The patient (or his family) has a right to treatment, even if it is likely to be ineffective	0 (8)	0 (7)	NS	NS
There is no problem. As long as treatment is not futile and the patient (or his representative) wants it, treatment should continue	0 (16)	0 (20)	NS	NS
Conflict about withdrawing treatment. Is it letting the patient die or killing him?	5 (15)	0 (45)	NS	NS
It is unclear what is best for the patient	9 (51)	8.5 (50)	NS	NS

ASBH, American Society for Bioethics and Humanities; ICU, intensive care unit; SMDM, Society for Medical Decision Making. Values in parentheses are proportions assigning the top two ranks. NS, not significant.

Table 5 Medians of potential additional information in case 2

Group	SMDM (n = 76)	ASBH (n = 305)	p, Mann-Whitney test	p, χ^2 test
Assessment of benefits between patients	3 (11)	0 (6)	NS	NS
Definition of futile medicine	6 (33)	6 (30)	NS	NS
Success rate at which an ICU bed would be cost effective	0 (0)	0 (1)	NS	NS
Guidelines on futility of treatment	5 (25)	6 (29)	0.01	NS
Patient's (or family's) preferences	7 (67)	7 (63)	NS	NS
Patient's current and future quality of life	7 (61)	7 (64)	NS	NS
Assessment of resource scarcity	3 (3)	3 (5)	NS	NS

ASBH, American Society for Bioethics and Humanities; ICU, intensive care unit; SMDM, Society for Medical Decision Making.
 Values in parentheses are proportions assigning the top two ranks.
 NS, not significant.

bed. The SMDM members assign more importance to balancing the competing interests, whereas ASBH respondents argue that only the interests of the patient in the ICU bed are relevant to the decision. Half of ASBH, but less than a quarter of SMDM members, agreed that patients should not be compared ($p < 0.001$). In this response, SMDM respondents take a more utilitarian perspective, as hypothesised, arguing that expected benefit is a legitimate criterion for selecting who should be treated.

By wide margins, both groups agree that the family alone should not be the decision maker (see tables provided online at <http://www.jmejournal.com/supplemental>). In all, 80% of SMDM members and 73% of ASBH members indicated that the family and others, or others should make the decision. Thus, they agree that although the question of discontinuing treatment should be discussed with the family (potential next steps), the family alone should not be the decision maker.

DISCUSSION

Our inquiries were directed at determining similarities and differences in how two quite distinct scholarly communities reason about two dilemmas in clinical medicine. For this reason we selected two cases, on the basis of expectations regarding differences in approach between the two communities. We had seen such differences in the arguments raised in the pilot study that was the basis of our survey questionnaire. The first case was a conflict between respect for autonomy and beneficence at an individual level, and the second reflected a conflict of social justice caused by scarce resources, possibly influenced by futility arguments.

One of our central theoretical presuppositions of this survey was that the so-called facts of the clinical case do not show inherently where or what the essential moral dilemmas are. We expected that the theoretical background of the different scholars would influence their perceptions of the moral dilemmas (as well as their solutions to them). Our hypothesis was that SMDM members, by training, are more strongly focused on assessing the outcomes to decide what the best decision would be. Underlying this view is the general positivist assumption that on the basis of empirical data we can know what the best decision is. This line of thinking is clearly reflected in the answers to the question on the additional information needed for case 1. SMDM respondents assigned more importance to forecasting the effects of alternative treatment strategies on the patient's quality of life and on estimating the chances of surgical complications. This utilitarian line of thinking was also present in the ASBH community, but deontologists and care-ethicists were clearly present as well. Using a deontology or rights–duties framework (eg, respect for autonomy and autonomy should be “the” guiding principle), outcomes are not the most relevant criteria for choice, as the ideal decision can be determined beforehand, without knowing the possible outcomes. Using a care-ethics framework, the caring relationship and the mutual responsibility for respecting that relationship are central topics. In such a framework, the criteria for the best decision are not clearly determined beforehand, are process oriented and, especially, information about values is important.

Our quantitative results did reflect to some extent what we had expected, with SMDM members giving more weight to

Table 6 Medians of the potential next steps in case 2

Group	SMDM (n = 73)	ASBH (n = 300)	p, Mann-Whitney test	p, χ^2 test
Weigh the interests of a patient in ICU bed and a patient on the waiting list	3 (23)	0 (12)	0	0.01
Estimate the medical consequences of no treatment to both patients and then decide whether to discharge one and admit another	0 (16)	0 (13)	0	NS
Do not compare patients! Only medical arguments for this one patient (in the ICU bed) are relevant	0 (22)	5 (49)	0	0.00
Offer treatment for even a small benefit (unless treatment is futile)	4 (19)	4 (21)	NS	NS
Explain to the patient's family that further treatment is futile.	7 (69)	6 (61)	NS	NS
Seek their consent to stop				
Follow family's wishes	5 (36)	4 (22)	NS	0.01

ASBH, American Society for Bioethics and Humanities; ICU, intensive care unit; SMDM, Society for Medical Decision Making.
 Values in parentheses are proportions assigning the top two ranks.
 NS, not significant.

the outcomes and the trade-offs, and ASBH members having patient autonomy trump other considerations more strongly. In both cases, however, we also found substantial similarities between the two groups in identifying the core problems, the information needed and the next steps that should be taken. In case 1, as hypothesised, bioethicists often endorsed a deontological conflict (beneficence *v* autonomy), whereas decision makers often indicated that patient preferences should have a role, which does not necessarily refer to an ethical issue. Both groups agreed that additional information about the patient's values was needed. Beyond that, the ASBH group emphasised more the conversation between the patient and clinician, whereas for SMDM, as expected, information on probabilities and outcomes of the alternative strategies was more central. Thus, for the SMDM group, the central issues revolve less around interaction and more around prognostic considerations. Further, although ASBH members ranked information on the patient's values the highest, substantial proportions of them also indicated that information on values of both the patient and the surgeon and on the decision-making process would be important. This may reflect a recent trend within the discipline of bioethics, by which the dominance of the principle of autonomy (or of the paradigm of principles in general) has decreased, and that alternative approaches such as care-ethics are emerging.¹⁵⁻²² It may also point to the fact that bioethicists seem to focus more on contextual elements of the case, rather than on just applying moral principles to clinical cases (a change from deductive approaches towards inductive approaches^{3,23}).

In case 1, the patient could participate in decision making, and most of the ASBH respondents favoured him as the sole decision maker, whereas members of SMDM were more evenly divided about whether other parties should participate in the decision making. This difference reflects greater emphasis by SMDM members on getting a favourable outcome (increased chances of living) for the patient, whereas ASBH members tend to give more weight to patient autonomy. Both communities, however, agreed that the patient's wishes should outweigh the surgeon's preferences.

In case 2, the groups agreed that the primary task is to explain to the family that further treatment is futile and to get the family to consent to discontinuing vigorous treatment. As expected, SMDM members gave somewhat more importance to balancing the competing interests of the two patients, but they agreed that resource allocation was secondary to considering the best interests of the patient in the case. ASBH respondents argued that interests of only the patient in the ICU bed are relevant to deciding whether to continue treating him in the ICU. Both groups agreed that the question of discontinuing treatment should be discussed with the family, but the family alone should not be the decision maker. The emphasis on patient autonomy that appeared in case 1 (where the patient could be directly involved in the decision) is moderated in case 2, where surrogates are required, and neither group insisted that the family was the sole legitimate surrogate, although this position is regularly defended in the US. Both groups agreed that the interests of the patient could be as fairly represented by the clinical team as by the family, although the family must surely be brought into the discussion.

The difference between the groups in identifying the decision maker in case 1 is a fundamental issue. As SMDM members are more inclined to determine the best treatment by means of expertise and objective knowledge, more of them see the decision as one that should be shared between the patient and professional experts. Members of ASBH are more focused on moral problems and moral agency, which automatically leads to the agent (patient) himself.

No clear conclusion can be drawn regarding the moral distinction between refraining from doing what we consider right (case 1) and consenting to doing something we consider wrong. For case 1, the two groups agreed about the two top-ranked core problems, even though the mean rank by the ASBH members for the beneficence–autonomy conflict was higher. About the next step, both groups also agreed that once the patients' decision is understood to be in line with his values, the surgeon should be convinced that not performing surgery may be a rational option. Both groups thus seem to perceive it as not a very strong dilemma. In case 2, even though agreement existed regarding the core problem, much more variation was seen regarding the next steps. This distinction between the two cases is in line with the fact that the right of a competent patient to refuse treatment, especially a risky treatment (case 1), is well established in both bioethics and medical decision making. Respect for autonomy trumps the doctor's obligation to benefit the patient, especially in cases such as ours when the benefit is uncertain owing to the risk of perioperative mortality. Still, given the closed answering options, we cannot really assess the effect of the different moral connotation of the two cases. We acknowledge that the content of the questions did not make it easy for respondents to communicate their reflections, if any, on this moral distinction.

This paper began with our observation that the two communities we studied communicate very little with each other. This impression is supported by the very composition of our sample: none of the respondents was a member of both SMDM and ASBH. The communities go to different meetings, read different journals, espouse different theories, use different concepts and different methods of case analysis. Despite these differences, there are many similarities in the actual decisions they reach in two clinical dilemmas. Why is this so? Firstly, the sample of cases is quite limited, and there may be cultural consensus on what is appropriate. Particularly in case 1, consensus on patient autonomy may trump all other theories.

Further, judging from the questionnaires, SMDM respondents did not answer the questions by drawing decision trees. Instead, they responded intuitively, as did ASBH respondents. Both groups are highly educated experts and their intuitions about these cases may be similar, shaped by their experiences, education and social class. This would fit with the work of Donald Schön,²⁴ which describes how, by reflecting on action, professionals enhance their learning and add to their repertoire of experiences, from which they can draw in future problem situations. Practitioners thus reflect on and learn from experience with the aim of encouraging the integration of theory and practice, which may lead to changes in knowledge, attitudes and behaviour, and which may lead to more similar actions in professionals from different backgrounds than we would expect on the basis of their professional training. Ethical theories emphasise different principles and sharp distinctions between principles characterise different theories. But when we get down to cases or to practice, clinical dilemmas have inherent conflicts between at least two defensible, worthy principles. Thus, in practice, members of SMDM look to more than maximising expected utility, and bioethicists give some weight to social consequences in practice even if they may give utilitarianism little weight as a theoretical principle. The quantitative nature of our questionnaire, with predefined options, would further enhance such an effect, and make respondents incorporate principles that by training were perhaps not the first ones they would resort to.

This study has several limitations. Firstly, it deals with only two cases. Differences between the two communities may be more clearly delineated by other cases. If we had used more

cases, however, the response rate would have been even lower than it was. Secondly, to be practical, we limited the scope of the inquiry to four questions and a multiple-choice response format. Other questions or other modes of inquiry (such as focus groups) may lead to identifying other commitments and differences. The questionnaire was based on such a qualitative investigation, however, with response options reflecting the findings thereof. We wished to evaluate the findings from this qualitative pilot in a larger sample. Thirdly, information about the sex and religious beliefs of the respondents was not collected, and these factors may have important effects on reasoning in these cases. Finally, the response rate was disappointingly low for both groups, and we do not know how this may have biased the findings. Possibly the low response rate inflated similarities between the groups, as it may be expected that those who are interested in the topic or sympathetic to our method were more likely to respond, and those respondents may also be more aware of the reasoning of the other group. If respondents consisted of the more utilitarian thinkers among ASBH members, this would result in answers more similar to those of SMDM members.

In conclusion, it seems that the lack of communication between the two groups is sustained more by disciplinary boundaries and differences in methods of case analysis than by fundamental disagreement about what should be done in particular cases. At least in the two cases studied, there are no fundamental disagreements about the appropriateness of particular actions in specific cases, although there are differences in emphasis—for example, about the desirable extent of patient autonomy. We believe that the separation of the communities is not morally and practically desirable, and that both communities can profit from increased interdisciplinary dialogue and cooperation.

ACKNOWLEDGEMENTS

This research was sponsored and supported by the Department of Medical Decision Making, Leiden University Medical Center, The Netherlands. It was planned and begun while ASE was Boerhaave Visiting Professor of Medical Decision Making at Leiden University, for which we acknowledge the support from the Leiden University Medical Center.

Authors' affiliations

A M Stiggelbout, B Molewijk, W Otten, J Kievit, Department of Medical Decision Making, Leiden University Medical Center, Leiden, The Netherlands

A S Elstein, Department of Medical Education, University of Illinois at Chicago, Chicago, Illinois, USA

Competing interests: None declared.

Ethical approval: The institutional review boards at the University of Chicago at Illinois, Illinois, USA, and the Leiden University Medical Center, Leiden, The Netherlands, reviewed and approved the study.

APPENDIX

CASE 1

During the course of evaluation of an unrelated problem, an asymptomatic abdominal dilatation of the aorta of 6.4 cm (aneurysm) is found in a 76-year-old man. (Normally, the aorta is about 3 cm.) He runs the risk that the aneurysm may rupture which in turn may cause death within minutes. Three possible strategies are identified:

- Perform surgery as soon as possible to replace the aneurysm with an artificial aorta.
- Regular follow up the aneurysm to see if it has grown. Discuss surgery with the patient if and when it becomes further enlarged.

- Do nothing, no surgery and no regular follow-up. Proceed as if the aneurysm had not been found.

The patient is participating in a study on decision support in cases of abdominal aortic aneurysm, and so receives a brochure with individualised risk information calculated from an evidence-based decision analytical model. The brochure provides the following model-based statistical information for both surgeon and patient.

Short-term risks

- Risk of rupture in the first year, 8% (75% of these will die)
- Risk of surgical mortality, 3%

Long-term risks	1-year survival (%)	Median survival (years)
Surgery	91	7
Watchful waiting	88	6
Doing nothing	88	4

The patient is a member of the Dutch Society for Free Euthanasia. He strongly dislikes surgery because of the risk of immediate death, the possible complications and the 2–6-month recovery period after surgery (tired, less appetite). He is married, happy with his life and prefers immediate death caused by a rupture to the surgery-associated risks. In line with these arguments, the patient's choice is "do nothing". The surgeon disagrees, but respects the patient's decision. The surgeon wonders if the patient would have chosen surgery if he had not participated in the study on decision support and had not received explicit information about risks through the risk information brochure.

CASE 2

An 83-year-old man, previously in good health and very active, develops a ruptured aortic aneurysm and undergoes a major surgery to repair it. He is moved to a surgical intensive care unit, where he develops multiorgan failure. He is put on a ventilator and renal dialysis. Dopamine and adrenaline are given to sustain his circulation at a reasonable level. Gangrene develops in his right foot, so that amputation of the foot (or even the lower leg) may be necessary in the future. The patient is anaesthetised to prevent him from pulling out the ventilator tube and is unable to participate in any medical decision making. He has made no living will or advance directive. His wife is emotionally distressed and seems to have difficulty in understanding how critically ill he is. The team of doctors believe that his wife is so emotionally distressed that she does not seem reliable, stable or trustworthy. Some members of the ICU team and the hospital administration argue that active treatment should be discontinued and only supportive treatment provided. Others believe that vigorous efforts for this patient should continue. Both parties of the argument provide reasons to support their positions. The next patient is already waiting to be admitted.

REFERENCES

- 1 **Beauchamp TL**, Childress JF. *Principles of biomedical ethics*, 5th edn. New York: Oxford University Press, 2001.
- 2 **Molewijk AC**, Stiggelbout AM, Otten W, *et al*. Implicit normativity in evidence-based medicine: a plea for integrated empirical ethics research. *Health Care Anal* 2003;**11**:69–91.
- 3 **Molewijk AC**, Stiggelbout AM, Otten W, *et al*. Empirical data and moral theory: a plea for integrated empirical ethics. *Med Health Care Philos* 2004;**7**:55–69.

- 4 **Nelson JL.** Moral teachings from unexpected quarters: lessons for bioethics from the social sciences and managed care. *Hastings Cent Rep* 2000;**30**:12–7.
- 5 **Weaver GR, Trevino LK.** Normative and empirical business ethics: separation, marriage of convenience, or marriage of necessity? *Business Ethics Q* 1994;**4**:129–43.
- 6 **Weisz G, ed.** *Social science perspectives on medical ethics*. Dordrecht: Kluwer, 1990.
- 7 **Zussman R.** The contributions of sociology to medical ethics. *Hastings Cent Rep* 2000;**30**:7–11.
- 8 **Solomon MZ.** Realizing bioethics' goals in practice: ten ways "is" can help "ought". *Hastings Cent Rep* 2005;**35**:40–7.
- 9 **Veatch RM.** Medical ethics: an introduction. In: Veatch RM, ed. *Medical ethics*. Boston: Jones & Bartlett, 1989:2–26.
- 10 **Childress JF.** The normative principles of medical ethics. In Veatch RM, ed. *Medical ethics*. Boston: Jones & Bartlett, 1989:27–48.
- 11 **Von Neumann J, Morgenstern O.** *Theory of games and economic behavior*. Princeton: Princeton University Press, 1947.
- 12 **Lusted LB.** *Introduction to medical decision making*. Springfield: Thomas, 1968.
- 13 **Raiffa H.** *Decision analysis: introductory lectures on choice under uncertainty*. Reading: Addison-Wesley, 1968.
- 14 **Tronto JC.** *Moral boundaries: a political argument for an ethic of care*. New York: Routledge, 1993.
- 15 **Walker MU.** *Moral understandings: a feminist study in ethics*. New York: Routledge, 1998.
- 16 **Hunink MGM, Glasziou PP, Siegel JE, et al.** *Decision making in health and medicine: integrating evidence and values*. New York: Cambridge University Press, 2001.
- 17 **Jonsen AR, Siegler M, Winslade WJ.** *Clinical ethics: a practical approach to ethical decisions in clinical medicine*, 5th edn. New York: McGraw-Hill, 2002.
- 18 **Teisseyre N, Mullet E, Sorum PC.** Under what conditions is euthanasia acceptable to lay people and health professionals? *Soc Sci Med* 2005;**60**:357–68.
- 19 **Guedj M, Givert M, Maudet A, et al.** The acceptability of ending a patient's life. *J Med Ethics* 2005;**31**:311–7.
- 20 **Solomon MZ, O'Donnell L, Jennings B, et al.** Decisions near the end of life: professional views on life-sustaining treatments. *Am J Public Health* 1993;**83**:14–23.
- 21 **Ubel PL, Dekay ML, Baron J, et al.** Cost-effectiveness analysis in a setting of budget constraints: is it equitable? *N Engl J Med* 1996;**334**:1174–7.
- 22 **Murray TH.** Communities need more than autonomy. *Hastings Cent Rep* 1994;**24**:32–3.
- 23 **McGee G.** Pragmatic method and bioethics. In: McGee G, ed. *Pragmatic bioethics*. Nashville, London: Vanderbilt University Press, 1999:18–29.
- 24 **Schön DA.** *The reflective practitioner: how professionals think in action*. New York: Basic Books, 1983.

bmjupdates+

bmjupdates+ is a unique and free alerting service, designed to keep you up to date with the medical literature that is truly important to your practice. bmjupdates+ will alert you to important new research and will provide you with the best new evidence concerning important advances in health care, tailored to your medical interests and time demands.

Where does the information come from?

bmjupdates+ applies an expert critical appraisal filter to over 100 top medical journals. A panel of over 2000 physicians find the few 'must read' studies for each area of clinical interest.

Sign up to receive your tailored email alerts, searching access and more...

www.bmjupdates.com