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Morten Magelssen

Reidar Pedersen

Centre for Medical Ethics

Institute of Health and Society

University of Oslo, Oslo, Norway

Ingrid Miljeteig

Department of Research and Development

Haukeland University Hospital, Bergen, Norway

and

Research Group in Global Health Priorities

Department of Global Public Health and Primary Care

University of Bergen, Bergen, Norway

Håvard Ervik

Clinical Ethics Committee

Møre og Romsdal Hospital Trust, Ålesund, Norway

Reidun Førde

Centre for Medical Ethics

Institute of Health and Society

University of Oslo, Oslo, Norway

Corresponding author:

Morten Magelssen

Centre for Medical Ethics

University of Oslo

Pb. 1130 Blindern

N-0318 Oslo

NORWAY

Email: morten.magelssen@medisin.uio.no

Tel.: +47 48223580

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The importance of systematic deliberation and stakeholder presence: A national study of clinical ethics committees

Abstract

Background. Case consultation performed by clinical ethics committees is a complex activity which should be evaluated. Several evaluation studies have reported stakeholder satisfaction in single institutions. The present study was conducted nationwide and compares clinicians' evaluations on a range of aspects with the CEC's own evaluation.

Methods. Prospective questionnaire study involving case consultations at 19 Norwegian CECs for one year, where consultations were evaluated by CECs and clinicians who had participated.

Results. Evaluations of 64 case consultations were received. Cases were complex with multiple ethical problems intertwined. Clinicians rated the average CEC consult highly, being both satisfied with the process and perceiving it to be useful across a number of aspects. CEC evaluations corresponded well with those of clinicians in a large majority of cases. Having next of kin/patients present was experienced as predominantly positive, though practiced by only half of the CECs. The educational function of the consult was evaluated more positively when the CEC used a systematic deliberation method.

Conclusions. CEC case consultation was found to be a useful service. The study is also a favourable evaluation of the Norwegian CEC system, implying that it is feasible to implement well-functioning CECs on a large scale. There are good reasons to involve the stakeholders in the consultations as a main rule.

Introduction

Clinical ethics case consultation is a demanding and often complex task which may influence decisions with serious consequences.¹ In order to raise the quality of this service, critical evaluations are mandatory. Four domains of quality relevant to case consultation have been characterised: ethicality, satisfaction, education and conflict resolution.² Several studies examine stakeholder satisfaction, which is generally found to be high – with health professionals giving the highest scores and next of kin and patients somewhat lower, but still mainly positive.^{3 4} In Schneiderman et al.'s multicentre study from an intensive care unit setting, ethics consultation received a positive evaluation by more than 90% of health professionals and 80% of patient surrogates.⁵

In the studies that evaluate stakeholder satisfaction, stakeholder views of the consult are rarely compared directly with the clinical ethics support (CES) service's own evaluation. One exception is a 1988 study from a US teaching hospital, where the clinician's and the ethics consultant's evaluation of the importance of the consult were consistent most of the time, with the consultant rating importance somewhat higher on average.⁶ Such comparison is potentially important, as it would disclose whether CECs and stakeholders judge the importance and success of various aspects and outcomes of the consultation similarly.

Few studies have evaluated case consultations on a national level. The present study is a nationwide study of the Norwegian CECs. We also wanted to improve on previous evaluation research by going beyond mere reports of clinician satisfaction, comparing the clinician's and next of kin's/patient's grading and free text evaluation with the CEC's own evaluation of the consult.

The Norwegian context in brief

Norway's (pop. 5.3 million) healthcare system is publicly funded. A special feature of the Norwegian hospital CEC system is the degree of standardisation, imposed formally by a national mandate⁷ requiring all health trusts to have a CEC, and specifying some aspects of structure and function; and through the role of the Centre for Medical Ethics (CME) at the University of Oslo, which by the Ministry of Health and Care Services has been given a national responsibility for coordination and support of the committees, including education of new members. This is likely to have produced a greater uniformity of committee structure and activities than in other European countries. Norwegian CECs typically perform consultations as a full committee, or with a smaller team of CEC members.⁸ CECs provide advice only; as decision-makers, clinicians are free to heed the CEC's advice or not. Many CECs use a simple six-step deliberation method to structure discussions.⁹

A 2008 Norwegian retrospective study surveyed 43 case consultations and found that half of the consultations were prospective, treatment limitation was the most common ethical problem, and the most common reasons for requesting a consult were to have a broad discussion of the case and to clarify the ethical problems.¹⁰ In an interview study, clinicians who had brought cases to the CEC found the case consultations useful.¹¹ Informants highlighted the importance of a systematic approach, the need to receive thorough information about the CEC beforehand, and the importance of being present at the committee's deliberation.

Methods

The main research questions were: What is the significance of ethics consultations for clinicians, patients and next of kin, how do they experience and evaluate taking part in the

consultations, and how does this compare with the CEC's own evaluation? All 38 Norwegian hospital CECs were invited to take part in the study, and 19 accepted. The study ran from September 2016 to September 2017, and was intended to survey all case consultations in the involved CECs within that 12-month period.

Three questionnaires were constructed; to the CEC itself, to clinicians, and to patients/next of kin who took part in CEC meetings, respectively. The purpose of the questionnaires was to record experiences with and outcomes from the CEC case consultations, emphasizing the outcomes that matter to the stakeholders.¹² There were also questions characterising the case itself and the CEC process. Some questions were similar or identical across the respondent categories. Questions were of different formats, some involving scoring on scales from 1 to 5 or from «strongly disagree» to «strongly agree», whereas others involved ticking boxes. Questions on what had been positive or negative about the consultation, what could be improved, and what consequences would result from the consultation sought answers in free text format. The questionnaires were constructed on the basis of a previous evaluation study,¹⁰ and refined through discussions among the researchers and piloting at one CEC.

The CECs each appointed a contact person for the study who received sets of questionnaires and distributed these to stakeholders after consultations. Questionnaires were coded so that questionnaires belonging to the same consultation could be compared. Questionnaires came with envelopes addressed to the Centre for Medical Ethics at the University of Oslo. Here, responses were entered into IBM SPSS 25.

Quantitative data were analysed through descriptive statistical analyses. Free text answers underwent qualitative analysis by the first and last author independently through a simple

thematic analysis approach.¹³ A brief post-study survey by email to contact persons asked about experiences with participation in the study.

Clinicians, patients and next of kin were informed about the study in writing. Completing and submitting the questionnaire was considered as consent to participate. CECs decided themselves from case to case whether their questionnaire should be completed by the leader, the contact person, or parts of or the entire committee.

Ethics approval

The study was approved by the Data Protection Official at the Norwegian Centre for Research Data (ref. 48902). In order to preserve the anonymity of patients and other stakeholders, the questionnaires contained no questions that could identify individuals.

Results

Characterisation of CEC consultations and cases

Questionnaires were received from 64 case consultations from the 19 CECs. The CECs report that they had 101 case consultations in the study period, resulting in a response rate of 63%.

When asked why cases were not included, contact persons most often pointed out that if they themselves were not present at the consultation, such as in some urgent cases, questionnaires would sometimes not be distributed. Forgetfulness and «evaluation fatigue» were also causes of non-response. On average, each CEC contributed 3.4 cases (range 0-8); the eight CECs at university hospitals each submitted 4.8 cases. Two CECs did not contribute any cases.

In 43 of the 64 cases, evaluations from at least one clinician was received in addition to the CEC's evaluation. 15 next of kin who participated in consultations were invited to evaluate,

yet only three evaluations were received. Two patients were invited, yet none contributed.

Due to the low participation of next of kin and patients, their responses were excluded from the analyses in this article.

Ten cases were retrospective, a further 16 principled or more general, and four uncategorised.

The remaining 34 were prospective cases concerning individual patients, and of these, nine were urgent cases. Retrospective cases were deliberated upon and completed within a median of 49 days, principled/general cases within 41 days and prospective cases within 7 days.

Table 1 shows who participated in the consultations. There were no cases where only a single CEC member consulted. A systematic deliberation method (such as the six-step CME model)⁹ was often used in prospective patient cases, both during the consultation itself (27/34 cases) and in the written report (28/34), but less often in retrospective or principled/general cases.

Table 1. Participants in CEC consultations (N=61)

Participant	No. of consultations
Full committee/most CEC members	52
2-4 CEC members	9
Clinician who contacted the CEC	46
Other clinicians	37
Managers	25
Next of kin	13
Patient	4
Patient ombudsman	2

The CECs were asked to indicate which ethical problems were defined during the consultation, selecting from a list of predefined problems known to occur often in CEC cases (Table 2). Respondents indicated on average 2.9 ethical problems. Limitation of life-prolonging treatment often involved several related problems, in particular autonomy (17 cases) and overtreatment (14). The other most common combinations were patient autonomy combined with uncertainty about competence to consent (15) or with next of kin's wishes (15).

Table 2. What kinds of ethical problems were defined during the CEC consultation? CECs' answers. Respondents could indicate more than one ethical problem. N=61.

Ethical problem related to	Number of consultations
Patient autonomy	34
Limitation of treatment for seriously ill	25
Priority setting and resource use	21
Next of kin's wishes	20
Information/communication	19
Uncertainty about patient competence to consent	18
Use of coercion (both somatic and psychiatric units)	18
Overtreatment	17
Confidentiality	6
Reproduction	5

Clinician evaluations and comparison with CEC evaluations

Overall, clinicians expressed satisfaction with the CEC consultation (Table 3). Scores were higher when the CEC had used a systematic discussion template than when not – for rating the meeting as a positive experience (4.93 vs 4.64), for recommending the CEC to colleagues (4.96 vs 4.69), and for learning how an ethical problem can be discussed (4.63 vs 4.08). The

CEC's own evaluation of how it had attended to the clinicians was concordant with the clinician evaluation in all but a couple of cases.

Table 3. Clinician and CEC satisfaction with aspects of the CEC consultation. Mean Likert scores (1=strongly disagree, 5=strongly agree). N varies from 51 to 53 for clinicians, and from 55 to 59 for CECs.

Aspect of CEC consultation	Clinicians' mean Likert score	Proportion of clinicians who disagree somewhat/strongly	CECs' mean Likert score*
CEC members met stakeholders with respect	4.96	0/53	4.90
Participating in the CEC meeting was a positive experience	4.82	1/51	4.64
Felt that I was listened to during the meeting	4.81	0/53	4.89
Received sufficient information about the CEC beforehand	4.68	1/53	4.68
Would recommend other clinicians in similar situations to discuss cases in the CEC	4.85	2/53	
I got to say what was important for me to say	4.77	1/53	
By seeing how the CEC works I learned about how an ethical dilemma can be discussed	4.44	3/52	
If I get into a difficult ethical dilemma again, I now know more about how to handle it	4.33	1/52	
The meeting gave me important new information	3.98	6/52	
The meeting changed my opinion	2.46**	21/52	

*: CECs were asked whether they thought the clinician had been met with respect, was likely to have experienced participation in the CEC meeting as positive, was listened to during the meeting and had received sufficient information.

** : Seven «somewhat agree», zero «strongly agree».

Clinicians also provided reasons for requesting a CEC consultation, and the perceived usefulness of the consultation (Table 4). Ninety-three percent of clinicians wanted a broad

discussion of the case and 64% wanted advice on the decision, yet there were also many other reasons for involving the CEC, with most respondents indicating multiple reasons. On average, clinicians who wanted to receive support for their own decision rated the consultation as most useful.

Table 4. The reasons given by clinicians for requesting a CEC consultation (multiple answers possible) and the perceived usefulness of the consultation in this respect (1-5 where 5 is highest). N=45.

Reason	Indicated by proportion of clinicians (% (N))	Average score for usefulness
Get a broad discussion of the case	93 (42)	4.50*
Be better equipped for similar cases in the future	67 (30)	4.40
Get advice about a decision	64 (29)	4.32
Get an external perspective	62 (28)	4.69
Get support for own decision	60 (27)	4.78
Learn from a difficult case	58 (26)	4.40
Clarify values at stake	44 (20)	4.70
Disagreement among professionals	31 (14)	3.50
Disagreement between professionals and patient/next of kin	27 (12)	4.33
Improve cooperation	22 (10)	4.00

*: Scores were higher when the CEC had used a systematic discussion template (4.67) than when not (4.25).

In free text answers, many clinicians noted that a broad discussion together with colleagues where light is shed on the issue is valuable and gives weight and support to the conclusion. A helpful part of the process was clarification and identification of what was at stake, so that genuinely ethical problems were highlighted and distinguished from practical or

administrative problems. Some problems experienced in the consultations were also noted: some complained that the presentation of the case was incomplete, biased, or the consultation was dominated by some of the discussants. Some clinicians also noted that the CEC's handling of the case was too slow for what they had required.

When asked about practical consequences of the consultation many clinicians answered that the most important consequence was assurance for themselves that their chosen course of action was appropriate. One physician wrote, «I dared to make the decisions I had planned for, even though a person who disagreed with me was against them». Among other consequences were the experience of increased competence, follow-up meetings with involved clinicians, ideas for seminars about general topics raised by a case, and the consideration of complaint or referral to relevant regional or national health authorities.

Stakeholder participation

CEC and clinician experiences with the participation of patients or next of kin in the consultations were predominantly positive (Table 5), and in several cases such participation led to new and important information being brought forth. However, stakeholder participation or conflict was sometimes also perceived as inhibiting frank discussions.

Table 5. CECs' and clinicians' answers to «If the patient/next of kin took part [in the consultation], how did you experience this?» Respondents could mark multiple answers.

Characterisation	CEC respondent N=16	Clinician N=17
Positive	15	14
Unproblematic	10	5
New and important information was revealed	6	3
Problematic because it was difficult to speak freely	1	3
It was difficult to clarify medical/professional information well enough	1	2
Conflicts inhibited the ethical discussion	2	0

In free text answers, many CECs and clinicians expressed that stakeholder participation (i.e., patients, relatives, professionals) in the consultation had been important. This was so because their views were significant, but also because participation in the process was a way to signal that they were taken seriously. Some stated that it could then also become easier for them to accept the CEC's advice and decisions that clinicians henceforth made. Conversely, many respondents lamented the absence of stakeholders that *ought* to have been present in the consultation. Some maintained that patient/next of kin involvement could also create its own challenges, such as when the patient had a mental disorder, or difficulty understanding the purpose and process of the consultation. According to a few clinicians, next of kin could sometimes take up too much space in the meeting, and being present could also be a strain on patients and next of kin. However, even in cases where the presence of stakeholders brought tension and conflict to the meeting, informants stated that stakeholder presence had been important.

Discussion

Norwegian CECs across the country handle a great variety of ethical problems in ways that are appreciated by clinicians. By inviting both referring clinicians and the CECs themselves to evaluate the meetings and process both quantitatively and qualitatively, we received a more nuanced picture of what they find useful, satisfactory and problematic, and the few instances where the clinicians and CECs diverge in their perceptions and evaluation of what takes place. Below we discuss the results in more detail.

CEC consultations are useful

Clinicians rate the average CEC consult highly, being both satisfied with the consult and perceiving it to be useful across a number of aspects. For the CECs, the present results confirm that their service is well received, and is often helpful in the handling and resolution of complex clinical-ethical cases. The average number of consults was fairly low (although comparable to other countries^{14 15}), and CECs could expand this part of their enterprise by systematically reducing barriers for clinicians to refer cases to the CEC.^{16 17} In our experience, clinicians deal with ethical problems recurrently and only ‘the tip of the iceberg’ reaches the CEC. In particular, there is a potential for taking on more urgent cases. However, this would also presuppose a requisite willingness, availability and resources on the part of the CEC. In our view, the CEC should ideally be able to assemble 2-4 members for urgent consults on short notice (4-24 hours) and clinical departments should be informed of the availability of this service.

Implementing CECs nationwide, with the degree of standardisation effectuated by the national mandate and the coordinating role of the CME, has been successful in that it has led to active CECs in most hospital trusts.⁸ To our knowledge, no other European national health

authorities have made the establishment of CECs or other types of clinical ethics support in all hospitals/hospital trusts a requirement.

What can explain the high degree of clinician satisfaction? Clinicians indicate that to a large degree, they received what they desired from the consult: they got to participate in a broad discussion of their own case in a forum attuned to uncovering important values at stake, employing ethics concepts helpful for putting into words the core clinical-ethical problems experienced. Notably, using a systematic deliberation method appeared to improve clinician learning about how ethics problems can be approached in practice.

The large degree of consistency between clinician and CEC evaluations indicates that the CECs, in general, can trust their own assessment of whether the consult fared well or not, and that self-evaluation in the aftermath of consults might be helpful in quality improvement. However, especially the free text evaluations from clinicians sometimes brought to light essential feedback for the CEC. Soliciting such feedback from clinicians might therefore aid the CECs in improving their practices.

Significance of the presence of stakeholders

There was almost a consensus that having next of kin or patients present in the meeting was positive; clinicians report slightly more disadvantages than the CECs. The presence of patients/next of kin can be of value in that they contribute important information or viewpoints, and as a way of including them as full partners in the moral dialogue. The latter corresponds with the ideals of discourse ethics, which is often referred to as one philosophical theory underpinning ethics consultation.¹⁸ If one or more participants dominate the discussion – as we saw some of the clinicians in the study complain about – then the CEC leader has a

crucial task in allowing every participant to contribute on an equal footing. Discourse ethics would stress that dialogue should be free of domination and that it is the quality of arguments made that should count, rather than participants' positions in the hospital hierarchy.

In the ICU setting, ethics consultation has been shown to facilitate consensus.³ Our study indicates that the CEC is perceived by clinicians as a suitable venue for handling disagreement between professionals and the patient/next of kin; to a lesser degree for disagreement among professionals. A potential explanation for the latter finding could be that professional/medical disagreement is more prominent when professionals disagree than is disagreement about moral values – and it is the latter kind of disagreement that CECs are equipped to address.

In our study, several respondents stated that there were stakeholders (next of kin and others) who ought to have been present in the CEC meeting. So why did only eight of the participating CECs involve patients/next of kin? In some cases, such as general/principled cases, such stakeholder participation might not be natural or feasible. However, the combination of high rates of clinician satisfaction, that consultations seldom led clinicians to change their views, and the fact that patients or next of kin were absent in the majority of prospective case deliberations, raises the question of bias on the part of the CEC.¹⁹ Having patients or next of kin taking part in discussions as equal partners would counteract any tendency of giving too much weight to the perspectives of clinicians. In cases of conflict, the presence of these stakeholders adds a deeper understanding of the reasons for the conflict, which can then be addressed. In an interview study with next of kin, many saw being invited to partake as potentially important and natural, or even as a matter of course.²⁰

How can participation by patients and next of kin be increased? First, patients and next of kin are often unaware of the CEC system, and CECs receive very few cases from them. More and better information, both within the hospital and to the public at large, would increase awareness of CECs and of how clinical ethics support could be helpful to them. Second, CECs should routinely consider whether the patient/next of kin ought to be invited to case deliberations. Third, good information about the CEC and what will take place in the meeting can lower thresholds to partake. Fourth, meeting a room full of ‘ethics experts’ can be intimidating for patients/next of kin (as indeed for clinicians). Consulting with only a few members of the committee, or having a pre-meeting where the patient/next of kin meet only one or two CEC representatives, might be seen as more comfortable for some. (However, in an interview study next of kin stated that they were comfortable with meeting a full committee.²⁰) Pre-meetings could also be helpful in cases where clinicians would feel inhibited to speak freely in the presence of patients/next of kin.

Limitations

Although the study was nationwide in including CECs in all major regions of the country, half of the Norwegian CECs did not participate. Apart from reasons of time and workload we do not know why CECs declined participation, but our impression from another survey is that participating CECs were among those with the highest levels of activity.⁸ The intention was to include all cases from the participating CECs, and the 63% response rate could mean that less successful cases have been left out. The number of consultations included (64) is not high. Having the evaluations of next of kin and patients would have enriched the study. Due to the low response rate among patients and next of kin, our aim to compare their evaluations to those of clinicians and CECs could not be fulfilled. Our hypothesis is that many of these stakeholders experience the situation they are in (leading to the CEC consult) as very

challenging, and that filling out a questionnaire in the aftermath of a CEC meeting was demanding too much of them. Perhaps it would have been better to study their experiences by means of interviews shortly after the discussion.²⁰ Finally, admittedly there are many other, and potentially better, ways to describe the taxonomy of ethical problems.²¹

Conclusions

The study shows that Norwegian clinicians who have used CECs perceive consults as helpful across a range of aspects. The study also indicates that it is possible to implement well-functioning CECs on a large scale to facilitate better handling of some of the most complex and difficult challenges that emerge in the healthcare services.

The study's comparison of clinician and CEC evaluations has led to the identification of potential for improvement of CEC practices in three areas in particular: First, both CECs and clinicians perceive the participation of next of kin/patients to be positive, helpful and important in most cases, and their involvement should therefore be encouraged. Second, a systematic approach to case discussions appears to be helpful didactically, aiding clinicians in understanding what ethical analysis is and how it can be performed. Third, CECs' self-evaluation of case discussions is valuable, and is likely to comport well with clinicians' views. However, clinicians will sometimes have important observations and correctives which can be sought and then used to improve the quality of the CEC's services.

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