

Is the discussion of patient cases in clinical ethics-committees useful?

Summary

Background. All health enterprises in Norway today have at least one clinical ethics committee (CEC). One of the aims is to give advice and to counsel the hospital staff on ethical issues.

As part of the quality assurance of this work, we wanted to find out if clinicians have benefited from these committees in individual cases.

Material and methodology. The local committees were requested to distribute a questionnaire to all clinicians who had submitted a case to the committee during the previous 18 months. The survey was anonymous. Out of the 86 questionnaires that were distributed, 43 (50%) were returned to the Centre for Medical Ethics.

Results. The majority of clinicians had a number of reasons for contacting the committee. The most usual reason was the desire to have a broad consultation on a case (70%), which was regarded as useful. The most common issue discussed was limiting the treatment of a seriously ill patient (56%), the will/wishes of the next-of-kin (40%) and patient autonomy (37%). The committee gave advice in 50% of the cases. Thirty-eight percent of the consultations resulted in practical consequences, including the discontinuation of treatment in six cases.

Interpretation. Because of the low response percentage, the results must be interpreted with caution. The work of the committees is generally evaluated as useful, and the consultations can have practical consequences. However, it is challenging to make this work better known among clinicians and to conduct quality assurance.

The article is Guro Kalager's compulsory project assignment as part of the programme of professional study in medicine.

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Clinical ethics committees have an inter-disciplinary composition. The members possess clinical expertise and ethics competency (1). Such committees can be found in the US and in most European countries. In 2003 the Ministry of Health and Social Affairs decided that all health enterprises should have an ethics committee. As of 1 January 2009, altogether 37 such committees had been established in Norway.

The work of the committee is to raise competence in clinical ethics and to promote a thorough and systematic treatment of ethical issues (1). The committee has no powers of decision but is intended to function as a form of support in decision-making and as a forum for clinicians and other affected parties in the discussion of concrete ethical problems, whether prospective or retrospective (1).

The Centre for Medical Ethics at the University of Oslo has been given responsibility for the national coordination of the committee work and for professional development. Quality assurance of the work is crucial if the committees are to play a role in grave decisions. National guidelines for decision-making processes for limiting the life-prolonging treatment of seriously ill and dying patients recommend the use of ethics committees in specially challenging cases (2).

In 2004 a quality assurance project was conducted in which interviews were carried out with committee members and healthcare professionals who had referred a patient case to an ethics committee (3–6). All the clinicians expressed the view that this had been meaningful but several of them stated that the threshold for seeking advice was high. In some cases such a referral was seen as disloyalty towards colleagues (4). The clinicians valued the systematic and thorough deliberations. It is a common problem, not only in Norway, that the threshold for discussing a case in an ethics committee is high and the committees are often little known among clinicians (7). In 2007, the Centre for Medical Ethics compiled a manual for the quality assurance and standardization

of committee work (8). A number of different sources (9–11) have called for assessment. It is probably most important to assess the discussion of ethical dilemmas linked to the treatment of individual patients. In this study we have investigated whether clinicians who have made use of the ethics committees to discuss individual cases found this relevant and useful. In addition, we have examined the type of cases reviewed and how they were dealt with.

Materials and methods

In May 2008 the Centre for Medical Ethics requested all ethics committees in Norway to pass on a questionnaire to all clinicians who had submitted cases to a committee from and including 2007. The survey was anonymous and clinicians were to be able to answer the questions without fearing that critical answers would be sent on to the local ethics committee or colleagues. Critical comments and input were regarded as being of special value. The questionnaire was returned directly to the Centre for Medical Ethics. To acquire an overview of the response rate each ethics committee was asked to report how many questionnaires it had distributed.

The form contained 27 questions, including why the ethics committee had been contacted (table 1), what ethical problems were in focus, how long it took before the case was discussed and what the outcome of the consultation had been. Moreover, a number of questions were asked about the usefulness of the ethics committee's consultation. Some of the questions were open questions, and some had space for comments.

The form was designed on the basis of the 2004 survey and on international experiences (12).

Results

Twenty ethics committees had passed on 86 questionnaires. Of these, 43 were returned to

Key points

- Clinicians found it useful to take up ethical issues in an ethics committee
- A number of the consultations had practical consequences
- Patients and next-of-kin were only directly included in the consultation to a limited extent

the Centre for Medical Ethics (50%). Not all questions were answered on all the forms.

Who contacts the ethics committees?

Twenty-three (54%) of those who had referred cases to the committee were physicians, 15 (35%) were nurses and two (5%) were psychologists. Three people (7%) had a different profession. The committee members themselves had initiated two (5%) of the consultations.

Table 2 provides an overview of the departments to which the patients belonged – the psychiatric department, the medical/neurological department and the intensive care ward were those most often represented. Fifty-one percent of the cases were discussed before a decision had been made (prospective) and 49% were discussed afterwards (retrospective).

Why was the ethics committee contacted?

Table 3 shows which ethical problems were defined. The most common was limiting the treatment of seriously ill patients, the will/wishes of the next-of-kin and patient autonomy.

Almost all of those who contacted the ethics committee stated that there were several reasons for the referral (table 1). Thirty people (70%) answered that they wanted a broad discussion of the case while 25 (58%) wished to acquire an «external perspective». Several mentioned that the discussion had shed light on the complexity of the case and provided a broader base for reaching a decision. Twenty-two participants (51%) had contacted the committee for advice on what decision they should make – 17 of these were prospective cases. Sixteen (37%) wanted to gain support for a decision they had already taken and ten of these were prospective cases. One person thought it was good to gain support for a decision that the next-of-kin had disagreed with, but commented that it was equally important that the latter's views were also heard by a third instance without responsibility for the treatment. This helped to ensure a more open process. In general there was little negative feedback, but one doctor whose decision had not been supported wrote: «It appeared to be a kind of trial in which I was to be called to account. To me it seemed that there was an excessively strong desire to comply with the patient's wishes, and at the same time a lack of understanding that patients do not always know what is best for them».

We also asked clinicians how useful the consultation had been (table 1). The consultation was found most useful when the clinicians needed advice prior to a decision, when they wanted to have a broad discussion of the case, when it felt reassuring to get an «outside perspective», and in order to be better equipped to deal with similar cases in the future. These were also among the most

Table 1 Reasons why clinicians (n = 43) contacted ethics committees and their evaluation of how useful the consultation had been based on the reason why they contacted the committee (1 = not useful, 5 = very useful)

	Reason for contacting the committee	How useful was the consultation (Scale from 1–5)?
	Number (%)	Number (score)
To have a broader discussion of the case	30 (70)	25 (4.1)
To clarify the ethical challenges	26 (61)	20 (3.7)
To get an «external perspective»	25 (58)	18 (4.1)
To be better equipped to deal with such cases in the future	25 (58)	19 (4.1)
To get advice on the decision	22 (51)	20 (4.1)
To learn from a difficult case	21 (49)	16 (3.9)
To get support for one's own decision	16 (37)	15 (3.4)
To clarify the values that were at risk	10 (23)	7 (3.7)
To improve cooperation	9 (21)	3 (2.0)
To share the responsibility	7 (16)	4 (3.5)
Because the case involved conflict	5 (12)	4 (3.3)
To create agreement	4 (9)	2 (4.0)
To learn more about ethics	4 (9)	4 (3.3)
Because the case was deadlocked	4 (9)	4 (3.3)
Other	5 (12)	3 (3.3)

important reasons for contacting the ethics committee.

The clinicians were least satisfied with the committee's contribution to improved cooperation and conflict processing.

Procedures

Thirty people (73%) had given the committee written information about the case prior to the consultation, eight of the committees (20%) had preliminary meetings with people who could give information, eight participants (20%) answered that all those involved were present during the consultation, and two had given information about the case through a prior interview.

Ten people (23%) said that the consultation took place only a few days after they had referred the case to the committee, seven (16%) had waited for a maximum of two weeks, 11 (26%) had waited from between two to four weeks and 15 (35%) had waited for more than four weeks. Eleven of those who had waited more than four weeks had a retrospective case. According to 37 of the clinicians (86%), the waiting period was acceptable.

After the consultation 33 participants (77%) received the minutes of the meeting. Eight (27%) filed this in the case record, eight (27%) recorded the conclusion in the case record, and 17 (57%) filed the minutes among their own documents.

Participants in the consultation

Thirty-one respondents (76%) stated that the entire committee/most committee members participated actively in the consultation

and eight (20%) said that some (2–4 members) participated. In one of the cases only

Table 2 The department to which the patient discussed by the committee belonged (n = 43)?

	Number (%)
Psychiatric department	12 (28)
Medical/neurological department	10 (23)
Intensive care ward	6 (14)
Gynaecological, surgical or oncological department	6 (14)
Neonatal/paediatric unit	5 (12)
Other	4 (9)

Table 3 What ethical problems were defined during the consultation (n = 43)?

	Number (%)
Limiting the treatment of seriously ill patients	24 (56)
The will/wishes of next-of-kin	17 (40)
Patient autonomy	16 (37)
Coercion directed at patient	9 (21)
Prioritising/resources	8 (19)
Information/communication	8 (19)
Pledge of professional secrecy	6 (14)
Ethical problems linked to reproduction	5 (12)
Other	6 (14)

Table 4 Who, apart from members of the ethics committee, took part during the consultation [n = 33]?

	Number (%)
Nurse/nursing staff	22 (67)
Physicians with relevant professional expertise	21 (64)
Departmental heads	11 (33)
Next-of-kin	5 (15)
A representative of the patient	0
Patient	0
Other	7 (21)

one member participated. Twenty-seven clinicians (63 %) had been present during the whole of the consultation. Six of the 15 who had not been present would have liked to have been present.

Table 4 gives an overview of those who participated in the consultation in addition to the committee members. Ten respondents felt that others should also have been present, e.g. a lawyer, a social worker, a specialist, a doctor responsible for the patient and the next-of-kin. The average attendance during the consultation was 9.4 persons (ranging from 4–20).

Participation of the patient/next-of-kin

No patients were present during the consultations (table 4), family members were present in five of the cases. In one case family members were invited but did not turn up.

Three of the five clinicians who were accompanied by family members said that this was unproblematic and positive. One commented: «It was good to demonstrate that the whole patient was so clearly the focus». All five had felt that they could speak openly and that the medical side had been well clarified. However, one person was of the opinion that a conflict of interests with the family had hampered the ethical deliberations and that the meeting had led to an increased level of conflict.

Outcome

Of the 42 who answered this question 21 (50 %) said that the ethics committee had given clear advice. For example, four had been advised to withhold further treatment/ to terminate ongoing treatment. The advice given in two cases applied to the use of coercion, and two clinicians were recommended to seek a second opinion or to refer the case to the chief county medical officer.

Twelve clinicians (31 %) felt that new aspects had emerged during the consultation, including principles for dealing with similar cases in the future.

Fifteen clinicians (38 %) stated that the consultation had resulted in practical consequences – in six cases further treatment was dropped/ongoing treatment was terminated. Another person writes that the committee's

deliberations were of significance in that greater attention was paid to ethical considerations afterwards.

Two answered the question on why the final decision was not in line with the committee's conclusions. They said that regard for the family, internal disagreement in the treatment team, pressure from lawyers/the media and the emergence of new information played a role.

Discussion

It is important to evaluate the work of the ethics committee for several reasons. It must be seen as a reliable system that can improve patient treatment, and it should be adapted to the needs of users to the greatest possible extent. The work must also be evaluated to justify the use of resources.

In this study we have approached healthcare professionals who have submitted individual cases to an ethics committee. The opinions of the patients and their next-of-kin are not represented. Studies conducted in other countries have shown that healthcare professionals are often more satisfied with the committee's deliberations on difficult cases than the patient and his/her family (13, 14). Several international studies show that healthcare professionals find the deliberations of the committee useful (13–15). It is to be hoped that the best interests of the patient are also safeguarded. However, the consultation can also be of importance in cases in which the clinicians do not gain full support for all their thoughts.

Who should participate in the consultation?

The Norwegian committees carry out their work in different ways. We have established that not all involved parties are routinely invited to take part in the consultation. No patients participated, and the next-of-kin only took part in 15 % of the cases. We do not know if this is to spare them from hearing information that can cause anxiety or if there is a concern that their presence will hinder discussions of difficult medical and ethical questions (8). Many ethics committees undoubtedly perceive healthcare professionals as their primary target group.

Communication problems and conflicts often play a key role when a case poses an ethical challenge for the clinician (8, 13). In cases where there is disagreement, one party should not represent the view of the other party. This weighs in favour of involving the patient, the next-of-kin or someone who represents the patient, particularly in prospective cases. In retrospective cases in which the learning principle assumes a greater role, it is not equally important that the patient is directly or indirectly represented. Nevertheless, the committee must always ensure that the perspectives of the patient and next-of-kin are adequately elucidated and stressed. Their participation will help to ensure that everyone gains a greater under-

standing of the complexity of the case, and can also reassure them that they are being taken seriously (16). It is noteworthy that the study shows that clinicians generally found it unproblematic and positive that family members participated in the consultation.

Among the clinicians who did not themselves take part in the consultation, several expressed the wish that they had been invited. The participation of all parties can help to clarify uncertainty and disagreement concerning facts and to promote improved dialogue (16).

Low threshold offer

The 2004 survey showed that many committees only dealt with a few cases (5, 6). For the committees, becoming better known in hospitals is a continual challenge. Studies have shown that there is a high threshold in medical circles when it comes to discussing problems with third parties, and many clinicians are afraid of criticism (5, 6). An ethics committee is intended to be a low threshold offer promoting the ability to reflect on ethical matters and is not meant to be a forum for moralizing and passing judgment (8).

For many busy clinicians it is important that accessibility to the services of the ethics committees is ensured and that there is a short period of time between the referral and the consultation. The survey showed that 35 % waited for more than four weeks, but this mainly applied to retrospective cases. Many committees can meet at short notice.

Previously the ethics committees have been criticized for deficient procedures and a lack of structure in the consultation (5). Few people have commented on this in our survey. Altogether 77 % received the minutes of the consultation, but in our opinion all those involved should receive these. This is resource demanding, but circulating the minutes ensures openness and access.

Outcome and usefulness

A key question is what determines whether the case consultation in an ethics committee is experienced as useful. The survey showed that the committees had given clear advice in only half of the cases. The most common reason for clinicians contacting the committee was the desire for a broad discussion. The cases that are handled by the ethics committees are often complex, and it is not always possible to identify one correct solution. In the final instance the physician in charge of treatment must make a decision. The deliberations of the ethics committee can be supportive in that the ethical aspects of a complex case are elucidated.

The survey showed that the consultations resulted in practical consequences in 15 cases (38 %) – in six cases further treatment was withheld or the treatment was terminated. The fact that the work of the committee is influential in decision processes in serious cases stresses the need for quality assurance.

Limitations

The survey has a number of limitations. The body of material is small, and there is a 50 % response rate. The survey was anonymous because we were particularly interested in critical feedback. This meant that we could not send reminders to the clinicians who had received the questionnaire. The Centre for Medical Ethics has the national responsibility for strengthening the quality of the work. The fact that the completed forms were to be sent directly to the centre may have influenced respondents to answer in a positive manner. Nor can we rule out the possibility that the ethics committees have sent the questionnaire to the clinicians that they assumed were satisfied.

We do not know how many cases altogether the committees have discussed during this period. The individual committee is not required to submit an annual report to the Centre for Medical Ethics, even though most do. Nor do we know why so many committees did not pass on the questionnaire. The 2009 annual report of the Centre for Medical Ethics showed that one in four committees had not discussed cases related to individual patients in the previous year (17). Our survey will not be relevant for these committees. Another reason for the low participation may be that the survey was commenced just before the summer vacation. Therefore we cannot be certain that our respondents are representative of the clinicians who have resorted to the ethics committees or that general conclusions can be drawn from the results. Our survey can only be regarded as a pilot study – a more system-

atic and representative review should be conducted at a later stage.

Conclusion

The survey indicates that healthcare professionals who have made use of ethics committees in individual cases found this useful. At a time when more and more is possible in the field of medicine, new ethical challenges will emerge. The ethics committees can make a positive contribution in such cases by ensuring that all involved parties are heard, and by shedding light on all aspects of the case – thus promoting ethically acceptable solutions.

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