

## CLINICAL ETHICS

# Clinical ethics, information, and communication: review of 31 cases from a clinical ethics committee

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**Objectives:** To summarise the types of case brought to the Clinical Ethics Committee of the National Hospital of Norway from 1996 to 2002 and to describe and discuss to what extent issues of information/communication have been involved in the ethical problems.

**Design:** Systematic review of case reports.

**Findings:** Of the 31 case discussions, (20 prospective, 11 retrospective), 19 cases concerned treatment of children. Twenty cases concerned ethical problems related to withholding/withdrawing of treatment. In 25 cases aspects of information/communication were involved in the ethical problem, either explicitly (n = 3) or implicitly (n = 22).

**Conclusion:** Problems related to information/communication may underlie a classic ethical problem. Identification of these "hidden" problems may be important for the analysis, and hence, the solution to the ethical dilemma.

Information is a prerequisite for active involvement in medical decision making. In 2002 the patient's right to information was confirmed by law in Norway. So far issues relating to patient information and communication have been given low priority in the education of physicians, in medical research, and possibly also in clinical ethics.<sup>1</sup> The Norwegian philosopher Knut Erik Tranoy has compared patient information to a drug, which may not only have the potential for healing but also a potential for side effects. It is the physician's responsibility to judge how much information should be given, when, and in which way.<sup>2</sup>

What constitutes the elements of "patient information" is no easy task to define. Patient information is usually conceived of as the medical facts given by the physician to the patient as a necessary basis for informed consent.<sup>3</sup> It is, however, conceivable that other signals, communicated verbally and non-verbally, may also influence how the patient interprets the information about the medical condition.

The creation of hospital clinical ethics committees (CECs) may reflect both the difficult ethical dilemmas raised by modern technology and the fact that physicians no longer have the only say in medical decisions.<sup>2-4</sup> Increasingly patients, patients' relatives, and other health professionals have become active participants in the decisions. In Norway the first CECs were established in 1996, and the CEC of the National Hospital in Oslo was one of the first. This hospital is a tertiary medical centre, responsible for highly specialised medicine. After serving for seven years in the CEC we have become increasingly aware of the important and complex issues related to patient information. The aim of this paper is to present issues that have triggered requests for ethics consultations and, in particular, to illustrate the role of information and communication in these ethical dilemmas.

## MATERIAL AND METHODS

The CEC has nine members: three medical doctors, two nurses, one physiotherapist, one hospital priest, one representative from the hospital administration, and one external consultant (a physician) with formal education in medical ethics. All hospital employees may initiate consultations. The CEC has a fixed two hour meeting scheduled once a month.

In a case of more urgent need of discussion additional meetings are arranged. The CEC's aim is to ensure open and thorough elucidation of a problem where all involved parties may present their views. The clinician in charge of the patient has the responsibility for the final decision.

The case discussions are planned as follows:

- clarification of the medical problem—for example, risks, prognosis
- identification of all "involved" parties
- identification and clarification of the ethical values, principles, and virtues at stake
- discussion of possible solutions and their consequences.

All the people involved in the care of the patient are present at the discussions. Particular care is taken to have someone who can represent the view of the patient/patient's next of kin.

After the meeting the chair of the CEC together with the secretary prepare a case report. This is distributed for critical comments and necessary supplementary information to all participants of the meeting. The final report is then available for the patient's medical record.

For this study both of us (both members of the CEC) independently reviewed the 31 case reports from 1996 to 2002, identifying the types of ethical dilemma in each case. This process disclosed that, in most of the cases, issues relating to problems regarding information/communication were part of the reason why a case had developed into a clinical ethical problem. We then discussed our analysis with each other and categorised the information problems according to Tranoy's drug metaphor: how much information should be given, the timing, and in which way. Seven cases exemplifying these categories are presented in this paper. They have been slightly changed to protect the identity of the people involved.

## RESULTS

Of the 31 case discussions (table 1), seven were initiated by members of CEC—of which four had been reported in the

**Abbreviation:** CEC, clinical ethics committee

**Table 1** Characteristics of the 31 case discussions in the Clinical Ethics Committee, National Hospital, Oslo (1996–2002)

Prospective cases	20
Retrospective cases	11
Children	19
Issues related to in vitro fertilisation or termination of pregnancy	5
Ethical issues related to withholding/withdrawing treatment	20
Issues related to information/communication:	25
explicit problem	3
implicit problem	22

media and thus triggered retrospective CEC discussions. The remainder were initiated by medical personnel in the hospital.

### Classic ethical dilemmas dominated

In all 20 cases concerning ethical problems of withholding/withdrawing treatment there was conflict among the involved parties, either among different healthcare professionals and/or between physicians in charge of treatment and the patient's relatives. Only three of the 19 discussions concerning children raised ethical dilemmas other than withholding/withdrawing treatment. In two of these parents' rights were central issues.

Six of the cases brought to the CEC were straightforward ethical problems where communication played a lesser role, for example, questions of parents' right to be present during complicated procedures and conflicts involving withholding or forgoing life prolonging therapy. Here there was no disagreement about medical facts, but about normative questions: What is the right thing to do?

The other 25 cases disclosed various ethical aspects of information and communication. In only three of these cases were ethical problems related to patient information the explicit reason for contacting the CEC. However, during the CEC discussions an additional 22 cases were found to involve information and communication problems, which could explain why the conflicts arose and why the cases were considered as difficult to solve.

### Information is like a drug

#### The content of information. How much information should be given?

The retrospective evaluation of the 31 cases confirmed that assessment of a clinical situation could vary between different groups of healthcare professionals, as well as among physicians. Our analysis also showed that ethical conflicts could arise because the physician in charge did not openly acknowledge the uncertainty of medical information—for example, scientific studies and clinical investigations. Another problem is how much of the facts should be communicated and to whom. This is illustrated in the first case.

#### Case 1 (prospective)

A 45 year old, previously healthy, divorced father with two daughters died from heart failure after 45 minutes of attempted resuscitation. The reasons for his death were quite unclear. The two children, his ex-wife, and his brother were present at his death. The patient's brother was appointed contact person for the family and the one to receive all information about the deceased. After this had been decided a close friend told the physicians that the patient had been a homosexual, and that he had chosen to keep this a secret

except from his former wife. It had been important for him to hide his homosexuality because he had an open professional life and was living in a small community. Presently, he had had no known sexual partner.

At the time of the CEC conference the doctors knew that the patient was human immunodeficiency virus (HIV) positive. The treating physician raised the issue: Should the HIV results be given to the family representative? Is this in the patient's best interests?

The ethical and the forensic problems raised in this case concerned both the posthumous reputation of the deceased, his family, and the possible protection of sexual partners who could have been infected. The ethical dilemma concerned the physicians' duty to prevent spread of the HIV infection and the duty to respect the interests of the deceased.

The postmortem examination concluded that it was unlikely that his HIV infection was the reason for his death. Consequently, the information given to the family concerning the cause of death was uncontroversial. However, to respect the patient's wish, the information about his HIV status, which was closely linked to his homosexuality should be treated with great care. The tracing of possible sexual partners at risk should be left to his ex-wife who already knew about his "secret".

#### Case 2 (prospective)

Part of the consideration of content/dosage of information is evaluating how the information may be perceived.<sup>3</sup> Is there a risk a person may be hypersensitive or "allergic" to certain information? Complications may occur if this is not considered in advance.

A 26 year old, 28 weeks pregnant woman underwent ultrasound examinations. The physician who performed the final examination informed the woman that the fetus had a lethal brain malformation. Birth was then induced prematurely not only in accordance with the mother's wishes, but also because it was considered to give the child a better prognosis. After birth, the child's condition improved much more positively than anticipated. The woman, however, strongly expressed that she wanted treatment to be withheld. The physician thought this was unethical. He felt he had a duty to save the life of the child. All the people involved experienced great difficulty in communicating with the mother.

In this case the discussion concluded that the absolute and pessimistic content of information given to the woman before birth could have induced or strengthened her feeling of hopelessness and rejection of the baby. If the ultrasound findings had been presented with reservation reflecting the uncertainty which always is associated with this kind of information, the mother might more easily have accepted treatment of her child. The prognosis of the child seemed to be so good, it would have been wrong not to treat the child actively. The CEC concluded that the mother needed support when treatment of the child was continued against her wish.

#### Case 3 (retrospective)

Cultural and religious backgrounds may influence how things said with the best of intentions may be interpreted in unexpected ways.

A child was born with a serious heart condition that could not be treated surgically. The parents, immigrants from a non-western country, were informed about the poor prognosis and that any treatment would only postpone death. However, it was emphasised that treatment would not be discontinued if they disagreed. Gradually over several weeks, the situation grew worse. The nurses felt that the child was suffering severely and that the suffering was being prolonged

by the active treatment. The parents, however, strongly resented withdrawal of treatment.

This case was planned as a prospective case discussion, but a few days before the scheduled meeting the child suddenly died. During the retrospective discussion, in the absence of the parents, it was agreed that this child had been treated too long at the expense of the best interests of the child and medical resources and contrary to the feelings and clinical judgement of the professionals. The committee also retrospectively found that according to the parents' religion and culture, the physicians' assurance that "nothing will be done unless you accept it" could have given the parents a sense of responsibility for the death of their child. This might have made it impossible for them to accept withholding the treatment. A paternalistic approach, stating that the physician would bear the responsibility of the decision that futile but life prolonging treatment must be withdrawn, might have been preferable to the parents and reduced the number of weeks of suffering for the child, the parents, and the nurses.

#### *Case 4 (prospective)*

Medical information from physicians is no longer the only source of "truth" for patients. Today, the internet and media are increasingly important sources of medical information. This can create conflicts and ethical dilemmas.

An eight year old boy had a third relapse of leukaemia, which was treated without success. The child was discharged in acceptable general health. The parents understood that any further active treatment represented a high risk and would most probably deprive the child of a good life during the time when he could live normally. After a while, however, the parents again contacted the hospital to discuss further treatment because their relatives and neighbours had read on the internet about the child's condition and alternative types of treatment.

The paediatricians asked the CEC for a consultation. Here it became obvious that the parents actually had accepted the situation and did not want the child to have his last days disturbed by aggressive and futile treatment. What they needed was help to cope with the feelings of guilt induced by their surroundings for not having "tried everything". The conclusion of the meeting gave support to the parents for not letting their own fear of loss override the best interests of their child.

#### Timing of information

##### *Case 5 (retrospective)*

A 50 year old woman with chronic respiratory failure underwent successful lung transplantation. Prior to the transplantation she received thorough information about the risks of treatment, including the increased risk for malignancy due to immunosuppressive medication. After the transplantation she was optimistic and looked forward to being a mother and a wife again. A few weeks after the transplantation, however, the physician responsible learnt that autopsy of the donor had revealed malignancy. It is thought that transplant recipients have an additional high risk of developing the type of tumour the donor had. Accordingly, the doctor felt that he had a duty to inform the patient about this. He also feared a lawsuit if the information was withheld.

The new information had a negative effect on the woman. She stopped being well adjusted and optimistic and her quality of life deteriorated. The hospital priest who had talked with the patient raised the issue in the CEC: Had this information been in the best interests of the patient and her family?

The discussion revealed that it would be in conflict with the principle of patient autonomy if the physician withheld important information. On the other hand, this patient already knew that she had an increased risk of cancer. The patient was being followed closely, the new information did not imply any benefit of a more careful follow up. Should the information have been postponed until the situation was more stable? The discussion concluded that the communication of the information in this case probably could have been postponed.

This case raised another question: Should transplantation protocols be developed to strengthen patients' rights to protect themselves from information without significant medical consequences, but with possible negative psychological consequences?

#### How should information be given?

Our analysis found that comments made by healthcare workers could be interpreted by patients/patients' relatives as factual information creating conflicts and ethical problems. This is illustrated in the next two cases.

##### *Case 6 (prospective)*

A child was born at 27 weeks gestation. Computed tomography and magnetic resonance imaging showed lack of cerebrum and hydranencephaly. He was discharged after intensive care. Some time later he had a shunt operation due to increasing head circumference. At the time of the case discussion (where the mother was present) he was one year old. He was fed through a tube—the meals took about two hours and he slept only intermittently for one to two hours. The physicians were critical of continued active treatment of the complications and argued that invasive treatment might cause suffering and perhaps was not in the best interests of the child. The parents wanted all types of infection treated in the same manner as for other children.

The neurosurgeon and the child neurologist confirmed that any reactions to external stimuli—for example, light or hunger were purely reflexive. There was no possibility for psychomotor development, but with active treatment the child could possibly live for many years.

The question arose: To what extent had the parents understood that the child had a vegetative condition without the possibility for development and with no ability to interact with his surroundings? Previously the argument of "relieving the child from suffering" had been brought into the discussion. Had the description of suffering made the parents believe that the child was able to consciously experience pain and to communicate? If so, this piece of information, given as an argument for restricting life prolonging therapy, had had an opposite effect on the parents.

When all medical facts had been presented, the mother understood that the child could not and would never be able to perceive anything of his surroundings. She now said she was willing to accept that active treatment could be limited.

##### *Case 7 (prospective)*

In this case statements intended to comfort and maintain hope were interpreted as factual medical information.

A one year old boy had an unknown genetic syndrome, with no psychomotor development since birth. He had problems swallowing, was dependent on constant oxygen supplement and had frequent lung infections, which required respiratory treatment. The ethical dilemma identified was a conflict between the physicians who regarded treatment as only prolonging the child's suffering and the parents who wanted the active treatment to be continued.

The discussion in the CEC revealed that some nurses had told the parents "never to give up their child". The nurses'

comments had made the parents suspect the physicians were not acting in the best interest of the child. The parents chose to believe only the comments which suggested hope of recovery. Here the CEC's suggested solution was to coordinate the information given to the parents by making information an explicit subject in the healthcare team and by documenting in the child's medical record what had been said to the parents and why. This was the only way to make the parents understand that further treatment was only prolonging the child's suffering.

## DISCUSSION

In the review of the 31 cases discussed in the CEC of the National Hospital of Norway classic ethical dilemmas related to withholding or withdrawing treatment dominated. However, as has been found previously, complex issues of communication and information may underlie the dilemmas leading to conflict between the various parties involved.<sup>5-7</sup> Insufficient, conflicting, and contradictory information led to frustration, unnecessary suffering, and unnecessary spending of healthcare resources.

When more people have a say in medical issues, conflicts regarding solutions of complex medical problems obviously become more frequent. This may explain why 19 of the 31 cases involved children—who have dedicated next of kin who fight for a say in medical decisions.

Ethical dilemmas around medical information frequently involve conflicts between the duty to inform and to respect patients' rights to autonomy, and consideration of the consequences of providing information counterproductive to the healing process.<sup>3</sup> We have chosen Tranøy's drug metaphor as a tool to describe the contribution of information and problems of communication in what may become clinical ethical problems. Here we deal with very complicated medical and ethical problems, and the examples given may fit in several categories. We may have defined informational problems too widely, however, our aim is primarily to illustrate that complexity of medical information may be underestimated.

Information should be seen as a vital part of patient care, but similar to a drug it should be individualised and handled with competency.<sup>8,9</sup> More information may not necessarily be better than less information, although it may free the physician of accusations of paternalism. Not only the content, but also how things are said may play a role.<sup>10</sup> The potential side effects of information should be focused on in clinical research, particularly processing of the presented information.<sup>3</sup>

One of the findings of our study was that unacknowledged disagreement on medical facts among the health professionals may complicate an ethical conflict. The CEC's emphasis on clarification of medical facts and uncertainties during the case discussions proved important in identifying these discrepancies. Recognising cases where medical knowledge is uncertain or controversial, as illustrated in case 2, may not be an easy task. Uncertainty of medical information is frequently not made explicit.<sup>11</sup> According to Katz "medical uncertainty is generally brushed aside as doctors move from its theoretical contemplation to its clinical application in therapy, and, even more so, in talking with their patients" (see reference 12 p. 36).

Another important finding of our study was that trivial or supportive comments, not perceived as information by healthcare workers, may influence a patient's and their proxy's perception of a clinical situation and thus become a source of ethical conflict. One way to reduce this problem is to make issues relating to information as explicit and central to team discussions as are diagnostic and therapeutic issues. Although physicians frequently underestimate the

importance of patient information, there are variations in the extent to which patients want to be involved in active decision making.<sup>8,9</sup> Therefore it is important to find out in advance whether some information may be unwanted, as illustrated in case 5.

Information is now part of patients' rights. The common perception by physicians that the law states in a simple and absolute way what is the right solution may, as illustrated in cases 1 and 5, represent a threat to the patient's best interests.<sup>1</sup> In our opinion, physicians need to be warned against an attitude biased towards what "the rules say" more than towards what the patient wants or needs. The risk exists that some physicians may interpret the law too simplistically, whereas good lawyers know that law does not necessarily have a simple solution!<sup>13</sup>

Prospective case discussions in the CEC have been met with resistance among physicians, fearing that this will take ethical discussions and ethical responsibility away from the bedside.<sup>4</sup> The discussions in our CEC did not function this way, first and foremost they served to thoroughly clarify the issues involved in the case. It is interesting to note that there were twice as many prospective as retrospective discussions. It may be emotionally more difficult to raise a retrospective case discussion. However, retrospective cases have great learning potential: What went wrong? What are the implications for future practice? We believe that the CEC case discussions have had practical and positive consequences in several cases (for example, cases 1, 3, and 7). To participate in an honest and emotionally difficult discussion, openness of personal fallibility and courage to present constructive criticism are needed. Medical culture traditionally lacks these qualities.<sup>14,15</sup> Competency in conflict management is an advantage during CEC discussions to promote a secure atmosphere.<sup>5,16</sup>

Health care is under increasing demands for efficiency paired with "consumers' rights" of patients. This implies an increase of ethical conflicts and underscores the need for including formal training in clinical communication and bioethics both in the medical curriculum and in postgraduate training.<sup>7</sup> The CEC is one arena where the clinicians experience a model/forum for case discussions, which can be implemented in multiprofessional case conferences on the ward.

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