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Doctors and clinical ethics committees: friends or foes?

_ Original article

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Abstract _ German and French abstracts see p. 49 & 50

Background: Whose interests should a hospital clinical ethics committee (CEC) serve? This is a particularly important question in conflicts regarding life and death decisions. This question has been raised in Norway by clinicians, politicians and lay people.

Method: A retrospective evaluation of six high conflict cases discussed in CECs, all dealing with forgoing life prolonging treatment to children. The information about the cases is taken from media coverage. The focus is on reasons for conflict and on the role of the CECs. The author was involved in the CEC discussion of four of the six cases.

Findings: Parents' distrust in the medical judgments seemed to be an important reason why conflicts developed. In addition value conflicts were obvious, but value aspects sometimes could be covered by clinicians in medical facts. When advice was given in the CEC, they all supported the doctors' decision. The child's best interest was the focus of the CEC. In only one of these cases did the CEC's discussion seem to have had practical consequences.

Conclusion: The most important function for a CEC is to secure that value issues are recognized and dealt with in a competent way. Neutrality issues cannot be ignored in the work of the CECs. Lay CEC members, open and systematic working procedures, transparency of arguments and early involvement of all involved parties including the patients and/or next of kin in the discussion seem to be important in order to address neutrality issues.

Key words: ethics; neutrality; conflict; parents; death

The first clinical ethics committees (CECs) in Norway were established in 1996. Because this initiative has been strongly supported by politicians, by 2007 most hospital trusts had established at least one CEC. In Norway nearly all hospitals are publicly funded and are organized in approximately 30 hospital trusts serving a population of 4,6 million people. The Section for Medical Ethics (SME) of the University of Oslo was mandated by the Ministry of Health and Care Services to coordinate the committees and to facilitate competency building for committee members. It is explicitly stated that the clinical ethics consultation service is only advisory; the responsibility for any clinical decision rests with the doctor in charge and legally with the hospital trust. The CECs are multidisciplinary. Most committees accept cases from clinicians as well as from patients or next of kin (1). The number of cases discussed in each committee varies. Most CECs use a specific strategy when discussing cases. Clarifying facts, identifying involved parties and relevant law regulations, and analysis of value conflicts are important components of their strategy (2). Most individual prospective cases are discussed in the committee. Individual ethics consultants do not exist in Norway.

Previous research indicates that CECs may be experienced as alien by clinicians and that bringing a case to be discussed in a committee may be experienced as whistle blowing or

meeting a court (3, 4). Accordingly, whom clinical ethics committees are for is a pressing question (3, 5). Are they primarily a decision making tool for clinicians (6), a forum to secure the interests of patients and next of kin (7) or can they serve both parties' interests? This question is particularly important in cases of conflicts between doctors and patients or next of kin. Disagreement and conflict may be important reasons why individual cases are brought before a CEC (2, 8). Most CEC discussions on these issues are conducted with little tension. However, during the last five years, six cases dealt with in a CEC have been strongly exposed in the media. These cases have induced critical questions both from the public and from politicians concerning the committees' neutrality and their ability to take the voices of patients and next of kin into consideration.

The «Kristina case», which will be presented below, forcefully brought this to public attention. In the aftermath of this case, the Ministry of Health and Care Services explicitly asked the SME to produce a manual to give guidance on the work of the CECs (9). This manual recommends that each committee should have at least two external members (e.g. a patient representative, a member representing society, a lawyer or an external ethicist). In addition, it is suggested that the committees follow specific procedures both in the preparation of

a case and in how the discussion is carried out. In addition, if possible, someone representing the values and interests of the patient or patient's next of kin should be present during the discussion. Finally the manual recommends that in high conflict cases the discussion should be conducted in a CEC at another hospital. These recommendations have been criticized by CEC members for transforming the CEC from a non-threatening venue where clinicians can seek guidance, into yet another bureaucratic body, a conflict board, or an ethical court which takes power and responsibility away from clinicians. The CECs, according to these critiques, must decide whether they want to be a decision making tool for clinicians or serve as a mini court in high conflict cases.

The aim of this paper is to analyze these questions in the light of six cases, all of which were discussed in a CEC, and which have been exposed in the media during the last five years. The aim is not to discuss the right decision in each individual case but to analyze some of the challenges which these types of cases represent to the work of a CEC.

For confidentiality reasons, the information about individual patients and their families presented in this paper is limited to what has been presented in the media coverage. Because more details have been exposed in the media in cases 3–5, these cases are described most extensively. The author of this paper is a physician and an ethicist employed at the University of Oslo to coordinate the work of CECs. As an external member of a CEC (2), she was involved in the discussion of cases 2 and 4–6 (table 1). The insight from these experiences is used in a retrospective reflection on the procedures that were used.

The cases

All the cases discussed in this paper deal with conflicts regarding the continuation of life prolonging treatment of seriously ill children. All cases were brought to the CEC by the clinicians in charge. In cases 2, and 4–6 (table 1) the CECs were contacted after the decision to stop active treatment had been taken, and after the parents had taken the cases to the media.

Table 1: Six high conflict cases discussed in clinical ethics committees

Case number Year	Child's condition	Parents' voices present	Parents' wish	CEC's advice	Results
1 2004	Intracranial bleeding	No	Stop life prolonging treatment	Does not give advice	Child alive in institution, severely handicapped
2 2004	Multiple malformations in several organs	Yes	Continue treatment	Forgo surgery, comfort care	Active treatment given for a year after CEC's advice. Child died
3 «Kristina» 2005	Irreversible brain injury	No	Continue treatment	No advice, Discussion only	Intensive care treatment for five months, child died
4 2007*	Trisomy 18	Yes	Ventilator support	Forgo assisted ventilation	Treatment forgone. Child died
5 2007*	Terminal cancer	Yes	Continue treatment	Comfort care	Child died two days after CEC's advice
6 2007	Serious brain injury	Yes	Ventilator support if necessary	Forgo assisted ventilation	Provisional suspension of clinical decision by Local Health Authority. Child alive

* Deliberated in an external committee

In all cases in which the CEC reached a conclusion, the clinicians' decision was supported. The CEC which discussed case 1 never gives advice, but regards itself as a forum where clinicians can discuss their ethical problems. In cases 3–6 the parents had contacted lawyers.

The dilemmas presented in all these cases were most strongly exposed in public through the «Kristina case» (case 3, table 1). Kristina was a four-year old girl who was buried under a landslide in September 2005 together with her mother. The mother died, but Kristina was resuscitated and treated in an intensive care unit. Due to extensive brain damage, the clinicians judged from the very start that the prognosis was extremely poor and therefore wanted to stop treatment after a few days. The child's serious prognosis was confirmed by two independent second opinions performed by specialists in two different hospitals. The doctors argued that an additional reason to stop treatment was that one could not rule out that the child might be

suffering. Her father strongly opposed withdrawal and this led to a serious conflict which was widely reported in the media. The case was taken to court by the father to get an interim measure, but the court ruled that the hospital had the right to decide to terminate treatment. An appeal was filed, but withdrawn after just a few days. After almost five months in the intensive care unit, the treatment was withdrawn and the child died. The National Board of Health scrutinized this case retrospectively and supported the clinical assessments done by the hospital.

Subsequent to the Kristina case, the question of the right of relatives to influence end of life decisions and their right to an independent second opinion in such cases have been topics of debate. The case was discussed in the local CEC, but due

to the father's deep distrust in the hospital, the CEC's link to the hospital was regarded as problematic. Members of Parliament suggested that a national and more independent clinical ethics committee with the authority to make a final decision ought to be appointed in similar cases in the future (10). The Department of Health and Care Services, however, has replied that this challenge can be met by improving procedures, and by careful composition of the existing local CECs, in particular by paying attention to the committees' neutrality and ability to take the voice of the next of kin into consideration. The Health Minister also asked SME to elaborate national guidelines for forgoing of life prolonging treatment to the seriously ill. This work is currently being finalized.

Shortly after the Kristina case two new «high conflict cases» (cases 4 and 5) happened in the same hospital. Case 4 was an infant born with trisomy 18 (non mosaic). His prognosis was judged to be very poor, he was dependent on a feeding tube, and when apnoea started to occur (one of the usual ways for these children to die), the hospital judged that the child should not receive artificial ventilation, due to the poor prognosis, lack of effective treatment, and possible prolongation of suffering. The father strongly opposed this decision and contacted lawyers and the media (11). Because of the high conflict level the hospital took the case to the CEC in another city, where the case was discussed with the father and his lawyer on a telephone line. The CEC formulated an extensive report in which the hospital's decision was supported. The main argument was that artificial ventilation was not in this particular child's interest because it would only prolong the dying process. The father took the case to court because he wanted the child to be kept alive in case new treatments should be found in the future. The court, however, supported the clinicians' decision and included parts of the CEC's report into its evaluation. The judgment emphasized that the hospital had based their final decision on a very thorough discussion in a CEC, that the committee had highly competent members, medically as well as ethically and legally, and also that it had included the father and his lawyer in the discussion.

In case 5, a girl with a malignant disease had received extensive and aggressive treatment. In spite of this her condition deteriorated. The clinicians agreed that the child was suffering, and that anything but comfort care would do more harm than good. Second opinion had been sought on several occasions. Her only sibling also had cancer. The child's parents wanted aggressive treatment to be continued, and believed that effective treatment might be found elsewhere. They hired a lawyer, took the case to the media, and made an appeal to the local Board of Health, which supported the hospital's decision. As this was the third media exposed conflict case in the same hospital the doctors were accused – including by colleagues – of being arrogant and insensitive to parents' needs (12). The conflict reached the Ministry of Health and Care Services who instructed the hospital to seek the advice of an external CEC. The reason why this case had not been deliberated earlier in the hospital's own CEC was that the doctors regarded this as a purely medical problem with only one sound solution.

As this was in the middle of the summer vacation, no existing CEC was complete enough to deal with the case on a short notice. Therefore, members from different CECs were appointed to establish an ad hoc committee together with a hospital lawyer and a patient representative. The discussion was based on the medical record, but included a telephone interview with the mother, as well as interviews with members of the nursing care team and the paediatrician in charge. The committee concluded that aggressive treatment was not in the child's best interest and that she was best helped by receiving good comfort care. The parents objected that the committee was not neutral and that health care personnel support each other. The child died two days after the hospital received the committee's conclusion.

In the sixth case, a mother and her lawyer approached the local Board of Health in December 2007 with two requests: to change the hospital's decision to forgo ventilation of her child, and also to judge whether the discussion in the CEC (in which the mother, her lawyer, and a friend, took part) has been conducted according to law. The local Board of Health judged the hospital's decision to forgo ventilator support as against the law (table 1).

Discussion

A limitation with the cases as they are presented here is that they are based on elements presented in the media, which are not always accurate and balanced. However, these media presentations form public opinion and pinpoint some challenges that the CECs have to address. The author of this paper has been part of some of the discussions in the CECs and this may of course bias the retrospective reflections. On the other hand, this may yield valuable insight (13) which can be used to highlight questions regarding procedures used by CECs in high conflict case discussions.

The cases presented here are exceptions, but very costly ones both for the families, the health care personnel involved, and for health care resources. In addition, the media exposure of these conflicts probably reduced the public's trust in health care and therefore made it more difficult to forgo life prolonging treatment. The death of a child is hard to accept and often gives rise to feelings of injustice and lack of meaning. Thus, in addition to difficult ethical life and death dilemmas, many people and strong feelings are involved in such cases.

The cases above illustrate that in spite of legal regulations stating that no one can demand futile treatment, it is still difficult for clinicians to withdraw treatment for children against the wishes of their parents. The law is one thing, but feelings that come into play when media expose a case, point to arrogant doctors who lack empathy, and in particular focus on the parents' desperate fight for their children's life, are another. In case 2 intensive and costly treatment was continued for a year after the CEC had been involved, and in case 3, intensive care treatment was continued for four months

after a decision to stop treatment had been made. The CEC's advice may only have had practical consequences for case 4. Following these cases, two polarities are seen. One consists of professionals who are worried that strong relatives with the help of media and lawyers will increasingly make it impossible for doctors to act according to the patient's best interest: to stop treatment which only prolongs suffering and the dying process. In some instances intensive care treatment seems to function mainly as existential help to parents who are unable or unwilling to accept reality. The other polarity consists of people who feel that relatives are given too little influence over life and death decisions. A few questions on how CECs should approach these difficulties merit reflection in the aftermath of these cases.

Is impartiality important?

Prospective discussion of a particular case in a CEC is a decision help for health care personnel (2–4). Committees which are not perceived as competent, and in particular those who do not take the medical parts of a case seriously when carrying out ethical case discussions, will not obtain trust (4). The retrospective evaluation of these six cases also shows how important it is to bring into the discussion the voices of nurses and paramedical staff who work at the bedside and can evaluate the state and suffering of children and parents. They can describe how the patient suffers, next of kin's reactions and ideas, the relationships between family members and patient, and the communication between clinicians and next of kin. These are all facts that may be relevant for ethical discussion. The cases above illustrate how important and how difficult it is for CECs to meet accusations of partiality. Case 5, was taken to an ad hoc committee in a different city, this committee had a patient representative, an ethicist and a lawyer as members, and the parents had the opportunity to speak to the CEC directly. Despite all this, the parents felt that the CEC was not neutral.

Although it is the clinician's responsibility to make the final decision and not the CECs, we know that one reason for clinicians to take a case to a CEC is to receive advice (4). If advice is given, the CEC may influence serious decisions (3, 5, 14–17). Accordingly, impartiality is important. The fact that all the CECs who gave advice supported the clinicians may have strengthened the impression that the CEC's impartiality is an illusion. This is not necessarily true. That CECs supported the clinical decisions in these high conflict cases may indicate that these decisions were made after careful assessments of all important aspects of a case (values included). However, another reason might in fact be that it is very difficult for a CEC to contradict the assessment of clinicians. An American study found that CEC supported the clinical decision in 43 out of 47 futility cases (15). If a CEC is rarely critical towards clinicians' judgments, and the reason is that these judgments are excellent, one may argue that discussion in a CEC is superfluous. If the reason is lack of courage, loyalty

conflicts, or fear of being perceived as alien by hardworking, well meaning health care personnel, then the CEC may also be looked upon as superfluous. Impartiality issues therefore cannot be neglected.

One may, however, argue that some case discussions deal with general ethical dilemmas which are discussed to find morally acceptable solutions. In such cases a committee's neutrality is less of a problem. Still, the voice of the patient or a patient representative is important in the discussion. Further, if a committee does not give advice, it may also be argued that neutrality is less vital. However, case 1 indicates that even when no advice is given, discussion without the next of kin's voice may reduce trust and credibility. In this case the parents blamed the committee for not letting them participate in the discussion. They felt that their voice had not been heard and the chosen solution was hard to accept.

Why did a second opinion not solve the case?

The cases presented show that the reason for conflicts in life and death decisions frequently seems to be that the patient's next of kin distrust medical judgement. A second opinion from another institution may be necessary. However, second opinions did not solve the conflicts in the cases described here. One explanation may be that deep distrust had already developed, so that no matter what was said or done, it would only confirm the parents' impression that the medical establishment was against them: they had but one option, to continue to fight for their child's life with the help of their lawyers and the media.

Another reason why a medical second opinion may not solve such a conflict, however, is that the conflict is largely based on differences in value judgements and that some of these value judgments are not addressed by the clinicians (18, 19). Different value judgements were important reasons for the «insolvability» of all these cases. The Kristina case involved several such implicit judgments. For example: a life with a severe head injury which requires permanent breathing support is still worth living; the parental tragedy is so overwhelming that the child should be kept alive as long as possible; any life, even with suffering, is preferable to death. The two last positions were part of cases 5 and 6 as well. In case 1 one value argument was: Why should parents not decide for their children when they have to live with the consequences of the decision? In this case the parents claimed that a life with a serious handicap was too heavy a burden for their child and for the rest of the family. The health care workers, however, argued that this child deserved a chance to live too, and that it was too early to be completely pessimistic about the prognosis (a mixed medical and value argument). Hypothetically some of these cases could perhaps have been solved if value conflicts had been acknowledged by health care personnel earlier and the case discussed in a CEC with the parents present (17).

Whom are the CECs really there for?

When the conflict is based on value disagreements, it is vital to acknowledge and analyse both clinicians' and parents' values. Bringing the parents' voices into the committee either directly or via a representative secures that their feelings and points of view are acknowledged. In high conflict cases, ideally, the committee members should have conflict solving ability. Conflict solving capacity and ability to create a confident and calm atmosphere may be a precondition for an open discussion (2, 17, 18). In some of the cases above, insight was gained into serious communication problems which were based on insurmountable differences in perceptions of reality, e.g. parents who believed that their severely brain damaged child was improving, or that God would soon bring the child back to life.

The evaluation of these six cases reveals that the CECs are neither purely a decision tool for clinicians, nor a mini court to secure the rights of parents. The best interests of the child have been the focus in all of these case discussions. The patient's best interest, of course, cannot be seen isolated from medical judgement or parents' judgements, and both of these include values. The CECs first and foremost task is to elucidate and analyse these value issues, crucially also to find how value judgments are hidden in «objective medical facts». It is here that the justification of their existence lies.

The cases above show that one reason for conflict may be that family members simply are not able to realize the child's possible prolonged suffering due to futile medical treatment (cases 2–6). The irony is, however, that in retrospect prolonged treatment may not have been in the parents' best interests either. In these cases, families helped by lawyers have been fighting a long and exhausting battle in the media and in the hospital. Perhaps these parents could have been best supported with existential help to accept and cope with the inevitable. Another possible reason for conflict in these cases may be clinicians' failure to communicate satisfactorily with the parents. If an early CEC discussion can be used as an assurance that all aspects (including values) of a difficult case have been looked into before a decision is made, this may also enhance communication. Again, the CEC is most helpful through the impartiality and the thoroughness of the discussion it can foster, rather than necessarily through its conclusions.

If life prolonging treatment is not in any of the involved parties' interests the crucial question is: how can such treatment best be stopped? This question can not be solved by means of this analysis. In addition to the CEC discussion, in cases 3–6 Local Boards of Health or courts have been involved. It is interesting to acknowledge that while the courts in case 4 supported the hospital's decision and based this support partly on the CEC's discussion, in case 6 the Local Board of Health ruled that the clinical decision (which also was based on a thorough discussion in the same CEC), was illegal.

Conclusion: lessons learnt

These cases reveal some of the pitfalls facing CECs in life and death situation. The CECs most important task is to elucidate and analyse values, including value judgments hidden in «objective medical facts». It is important to do this early enough to promote discussion before all trust has been lost. In the cases outlined here, this was not done. Further, it is important to ensure that value aspects of a case are acknowledged upfront, and that all involved parties know that they are being taken seriously. If these conditions are realized, however, discussion in a CEC may indeed be a valuable decision aid for clinicians. The most important challenge for a CEC is thus not primarily to give advice and be experienced as a mini court, but to secure that value issues are recognized and dealt with in a competent way.

It is further important that such complicated cases should be discussed by means of open and transparent procedures. Good quality medical information and information from members of the nursing care team as well as patients' and next of kin's voices (directly or via a representative) are obligatory as a foundation for discussion. Finally, detailed minute reports from the deliberation, where all the arguments are presented, secure transparency.

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Zusammenfassung

Ärzte und klinische Ethikkommissionen: Freunde oder Feinde?

Hintergrund: Wessen Interessen sollte eine klinische Ethikkommission [CEC] eines Spitals befriedigen? Dies ist besonders im Hinblick auf Konflikte bei Entscheidungen am Lebensende eine wichtige Frage, die in Norwegen sowohl von der Ärzteschaft und Politikern als auch von Laien aufgeworfen wurde.

Methode: Evaluiert werden retrospektiv sechs in CECs diskutierte Konfliktfälle, die alle lebensverlängernde Behandlungen bei Kindern betreffen. Die Informationen über diese Fälle entstammen der medialen Berichterstattung. Der Fokus gilt zum einen den Gründen für die Konflikte und zum anderen der Rolle der CECs. Der Autor war bei vier von den sechs Fällen in die Diskussion der klinischen Ethikkommission involviert. **Ergebnisse:** Das Misstrauen der Eltern gegen medizinisch begründete Urteile konnte als einer der wichtigen Gründe für die Entstehung von Konflikten beobachtet werden. Ebenfalls eine Rolle spielten Wertekonflikte; die daraus folgenden unterschiedlichen Gesichtspunkte wurden aber durch die Ärzteschaft durch medizinische Tatsachen verdeckt. Wenn eine CEC um Rat gebeten wurde, haben alle die Entscheidung der Ärzteschaft unterstützt. Der Fokus der CEC galt dem Wohl und besten Interesse des Kindes. In nur einem der sechs Fälle hatte die Diskussion der CECs anscheinend praktische Konsequenzen.

Schlussfolgerung: Die wichtigste Aufgabe, die eine klinische Ethikkommission zu erfüllen hat, besteht darin, dass unterschiedliche Wertauffassungen als solche erkannt und in einer kompetenten Art und Weise behandelt werden. Die CECs sind ausserdem geboten, sich neutral zu verhalten. Am besten gelingt dies, wenn die Kommission Laienmitglieder umfasst, wenn die Arbeitsprozesse offen und systematisch und die Argumente transparent sind und wenn alle von einer Entscheidung betroffenen Parteien – inklusive Eltern und/oder Angehörige – zu einem frühen Zeitpunkt in die Diskussion miteinbezogen werden.

Résumé

Médecins et comités d'éthique clinique: amis ou ennemis?

Contexte: Quels intérêts devrait défendre un comité d'éthique clinique (CEC) hospitalier? Il s'agit d'une question particulièrement importante dans les conflits qui entourent des enjeux de vie et de mort. Cette question a été soulevée en Norvège par des cliniciens, politiciens, et membres du public.

Méthodes: Une évaluation rétrospective de six cas fortement conflictuels discutés dans des CECs, et qui concernaient tous le retrait d'un traitement de maintien en vie chez des enfants. L'information sur ces cas est tirée de la couverture médiatique. L'analyse est centrée sur les raisons du conflit, et le rôle des CEC. L'auteure était impliquée dans le CEC lors de la discussion de quatre des six cas.

Résultats: La méfiance des parents vis-à-vis de la décision médicale semble être une raison importante dans le développement de conflits. Des conflits de valeurs étaient également apparents, mais ces aspects liés aux valeurs pouvaient parfois être couverts par les cliniciens dans des faits médicaux. Lorsqu'un conseil était donné par un CEC, tous ont soutenu la décision des médecins. Le meilleur intérêt de l'enfant était le point central pour le CEC. La discussion du CEC n'a eu de conséquences pratiques que dans un cas.

Conclusion: La fonction la plus importante pour un CEC est d'assurer la reconnaissance, et une approche compétente, des enjeux de valeurs. Les enjeux de neutralité ne peuvent être ignorés dans le travail des CEC. L'inclusion de membres du public, des procédures ouvertes et systématiques, la transparence des arguments, et l'inclusion précoce dans la discussion de toutes les personnes impliquées y compris les patients et/ou leurs proches semblent importantes pour aborder ces enjeux de neutralité.

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