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Discussing End-of-Life Decisions in a Clinical Ethics Committee: An Interview Study of Norwegian Doctors' Experience

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Abstract With disagreement, doubts, or ambiguous grounds in end–of-life decisions, doctors are advised to involve a clinical ethics committee (CEC). However, little has been published on doctors' experiences with discussing an end-of-life decision in a CEC. As part of the quality assurance of this work, we wanted to find out if clinicians have benefited from discussing end-of-life decisions in CECs and why. We will disseminate some Norwegian doctors' experiences when discussing end-of-life decisions in CECs, based on semi-structured interviews with fifteen Norwegian physicians who had brought an end-of-life decision case to a CEC. Almost half of the cases involved conflicts with the patients' relatives. In a majority of the cases, there was uncertainty about what would be the ethically preferable solution. Reasons for referring the case to the CEC were to get broader illumination of the case, to get perspective from people outside the team, to get advice, or to get moral backing on a decision already made. A great majority of the clinicians reported an overall positive experience with the CECs' discussions. In cases where there was conflict, the clinicians reported less satisfaction with the CECs' discussions. The study shows that most doctors who have used a CEC in an end-of-life decision find it useful to have ethical and/or legal aspects illuminated, and to have the dilemma scrutinized from a new perspective. A systematic discussion seems to be significant to the clinicians.

Keywords Clinical Ethics Committee (CEC) · End-of-life decisions · Law · Evaluation · Composition · Conflicts

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Introduction

Clinical ethics consultations have obtained increased importance in Europe over the past decade, and since the 1980s many countries have established Clinical Ethics Committees (CECs) (Dörries et al. 2011; Pfäfflin et al. 2009; Hurst et al. 2007a, b).[1] In Norway, all 23 hospital trusts have at least one CEC. With the rise in prevalence of CECs, there are, as Marcus and colleagues emphasize, valid questions regarding the appropriate role of these bodies in the resolution of clinical ethical dilemmas (Marcus et al. 2015). The involvement of nurses and members from other professions, like legal practitioners and priests, has undermined the traditional hierarchical and doctor-dominated decision-making (Bahus 2014). Having more people involved in a medical decision may also increase the likelihood for disagreement.

In Norway, CECs have a consultative, supportive and educational function, and the main function of the CECs' discussion is to secure that value issues are recognized and dealt with in a competent way (Førde 2008). The responsibility for the final decision rests on the responsible physician. Some of the most difficult cases a doctor has to deal with are limitation of treatment at the end of life (Hurst et al. 2007a). Very often, such cases are complex medically, ethically and legally.

Norwegian doctors who regularly deal with end-of-life decisions rarely involve a CEC for ethics support (Bahus 2013). Barriers to requesting ethical consultation is probably a challenge (Gacki-Smith and Gordon 2005). Although doctors regularly make difficult decisions, they have no tradition for involving resources outside the medical team. In particular, doctors do not have a tradition of involving expertise other than health care personnel to reach a well-founded decision (Bahus 2014). The CECs' base line that no profession or person knows the whole truth in value dilemmas is contrary to traditional paternalistic decision-making in hospitals. However, recent public guidelines for end-of-life decisions state that in cases with disagreement, reservations, or ambiguous grounds, doctors are advised to involve a CEC.[2]

There is no formal or regulatory governance framework for Norwegian CECs, nor any defined educational requirements or specified core competencies for their members. There is no consensus as to the main role of a CEC; whether the CEC should be limited to a consultative, supportive body, have an educational function, or have a conflict solving and mediation function. Closely linked to its role is the CEC's composition, including the members' skills, knowledge and personal attributes.

It is emphasized that how health care professionals view the role of ethics committees in resolving ethically challenging situations is relevant for the work of these bodies (Marcus et al. 2015). As stressed by others, clinical ethics support services will be most useful if they are brought forth to match the ethical concerns of clinicians, and the perceived relevance of clinical ethics consultation rests with its

[1] Dörries et al. (2011), Pfäfflin et al. (2009) and Hurst et al. (2007a, b) with further references.

[2] Report IS-2091. https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/67/IS-2091-Beslutningsprosesser-ved-begrensning-av-livsforlengende-behandling.pdf (only in Norwegian).

ability to address the concerns of health personnel (Hurst et al. 2007b; Marcus et al. 2015). This study is a contribution to increasing the knowledge of doctors' evaluation of involvement of CECs in end-of-life dilemmas.

Methods

Study

The study has a qualitative approach. The inclusion criteria were doctors who had referred an end-of-life-decision to a CEC, or had been a member of a medical team which had requested the assistance of a CEC.

We recruited informants by first presenting the study at an annual national conference for CEC members, and secondly by asking CEC members to contact doctors who had brought an end-of-life decision to a CEC, to ask them if they were willing to share their experience through the study. The selection of study participants in this study was pragmatic and strategic.

We completed fifteen interviews in the period from 2006 to 2009. The first author carried out all the interviews. Most interviews took place in an office at the hospitals where the doctors worked.

The interviews were based on a semi-structured interview guide. Open-ended questions covering the following topics were used: why the CEC was needed, including what the participants wanted to achieve by involving the CEC, evaluation of the particular CEC's discussion, the CECs' composition, the result of the CECs' discussion, the doctors' overall experience with the CEC, and the doctors' view of the legal situation of end-of-life decisions in Norway. The interview typically started with the questions, (1) "Can you describe the setting and reason for bringing the end-of-life-case to a CEC?", and (2) "Can you describe the ethical dilemma?". The interviews lasted 30 to 90 minutes, were tape recorded and transcribed verbatim by the interviewer.

For validation, both authors have studied the transcriptions separately. The analysis of the text is inspired by the term "bricolage" meaning that we have moved back and forth in the text without leaning on one particular method or technique (Kvale and Brinkmann 2009). We have concentrated and categorized the text according to outlined themes (statements about the CEC's routines and composition, the role of the relatives, knowledge of law and ethics, and the doctors' overall experience). In this paper, we focus on the ethical dilemma in the end-of-life-decision the doctors asked for support to resolve, and in particular, whether the ethical dilemma contained conflicts or disagreement about life-prolonging treatment, or whether it was an ethical dilemma with uncertainty about the ethically preferable solution. Further, we focus on the doctors' expectations of what a CEC discussion could add to the decision-making process, their evaluation of the CECś composition, and their overall experience of having discussed an end-of-life decision in a CEC.

As a validation of the interpretations of the interviews, the first author has presented different aspects from this study in national and international forums. Some of the interviewed doctors have read their transcribed interviews.

Ethics

According to the Health Research Act (ACT 2008-06-20 no. 44: Act on medical and health research (the Health Research Act)) this project did not need to be submitted to a research ethics committee. Norwegian Social Science Data Services has approved the project.

Results

Participants

The doctors, 5 female and 10 male, were from nine different hospitals from six different locations in Norway. In five interviews, the patients involved were adults, the last ten involved minors. Two cases were discussed more than once because of new ethical aspects, and a third case because of a high level of conflict. Thirteen informants had participated in the CEC discussion, two of them the second time the CEC was involved. The reasons why two informants were not present in the discussion at all were that one doctor was not invited by the CEC to be present, and the second chose not to be present due to his position as a CEC member, and lack of availability at the time of the CEC meeting. In five of the discussions, relatives were present in the discussion. In three of these, lawyers accompanied the relatives.

Table 1 The ethical problem for discussion, the doctors' main expectations towards CECs, and the doctors' overall experience

No.	Ethical problem	Expectations of CECs	Overall experience
1	Conflict with relatives	Formality	Negative
2	Uncertainty	No expectations	Positive
3	Uncertainty	Moral backing/counter-arguments	Positive
4	Uncertainty	An outside perspective/advice	Positive
5	Uncertainty	Broader illumination/advice	Positive
6	Uncertainty	Broader illumination/advice	Positive
7	Uncertainty	An outside perspective/moral backing	Positive
8	Conflict with relatives	Broader illumination	Positive
9	Uncertainty	Advice	Positive
10	Conflict with relatives	Advice/moral backing	Positive
12	Conflict with relatives	Broader illumination	Negative
13	Uncertainty	An outside perspective/moral backing	Positive
15	Conflict with relatives	Advice	Positive
16	Uncertainty	An outside perspective/broader illumination	Positive
17	Conflict with relatives	Formality	Negative

No 11 and 14 did not fulfill the inclusion criteria

Thirteen out of fifteen informants were familiar with the CECs' existence, while two informants had only recently heard about the CEC.

Ethical Dilemmas Involved in the Cases

In addition to ethical problems related to end-of-life decisions, the informants outlined different ethical dilemmas related to conflicts with the patients' relatives (6/15 interviews). In 9 of the 15 cases, there was uncertainty about the ethically preferable decision (Table 1). None of the interviewees had any doubt about the patient's medical condition. The challenges seemed to be of an ethical, legal, and communicational character, including questions of whether it was right to offer severely sick patients respirator treatment, or withdraw nutrition and hydration. Two doctors (numbers 2 and 4) mentioned the difference between pediatricians' and anesthesiologists' view of whether a patient should be offered respirator treatment. One (number 4) of them narrates"…each time the child has been ill the mother has been reluctant to contact the hospital. Because maybe my child may not get to live. If I meet this particular doctor, then I know they do not want to put my child on a respirator. If I meet another doctor he might offer my child a respirator."

Dilemmas related to conflicts or disagreement involved both minor and adult patients. In all these cases the next of kin wanted life-prolonging treatment that the medical team found purposeless, and also unethical, because it prolonged suffering.

Disagreement within the medical team was a theme in four cases but not always admitted openly by the informant, and in two additional cases, the informant reported a partial disagreement with the conclusion of a second opinion from another physician.

Dilemmas related to uncertainty, meaning no obvious ethically right solution, included both situations when the medical team did not know whether prolonged treatment was in the patient's best interest, and when they concluded that it was medically preferable to stop life-prolonging treatment, but they were uncertain whether this was legally and ethically acceptable. Some of the interviews revealed insufficient ethics and legal knowledge. One informant (number 3) narrated "you think this is pfassive euthanasia, to end [life-prolonging treatment] and that it will be wrong […] ethically wrong, legally wrong." Uncertainty about the patient's future quality of life was included in the question about the ethically best solution. One doctor (number 4) narrates, "and that was perhaps what I thought was the biggest ethical problem, […] who is to say whether this child has good enough quality of life to live on further. Who is to say he hasn't."

The Doctor's Reason for Contacting the CEC

The CEC was contacted for several reasons: to receive moral backing for a decision already made, to obtain an elucidation of the ethical aspects of the case, to receive concrete advice, and to have the case discussed by people not directly involved in the case, but also combinations of these reasons (Table 1). One doctor (number 13) narrated: "So the intention to refer it to [CEC] was […] simply to discuss it in a forum which was […] having some distance to the case. […] and we wanted to hear

what they thought and […] whether we got a sort of support for what we had been thinking and doing […]."Another doctor (number 16) said "in order to approach the problem openly we chose to involve the hospital's ethics committee […] to illuminate different aspects of the case."

An informant (number 5) told us that it was difficult to know what the patient (with consent competence) wanted, since it was hard for him to communicate, and that it therefore was ethically complicated, particularly since he was so young. Another informant (number 6) told us that his case involved a relatively young, mortally ill patient. He wanted advice about whether life-prolonging treatment should be stopped, and on which grounds. The informant found the case especially difficult since the patient had children.

Composition of CECs

The composition of CECs seems to be of importance. An interdisciplinary composition including a legal practitioner was emphasized as preferable. Two doctors (numbers 3 and 13) stated that they missed legal competence in the committee. One of these (number 13), commented that health personnel were overrepresented in the CEC. On the other hand, several informants felt that part of the CEC's competence was familiarity with the clinical reality. Personal skills among CEC members was emphasized by one doctor (number 7), who pointed out that personality matters.

Medical Culture and Power

A few informants emphasized the threshold for involving the CEC being too high; one stated that many colleagues were opposed to involving the CEC (number 5). This informant was also insecure about whether her dilemma was suitable for a CEC discussion. The informant (number 5) told us, after the tape recorder was switched off, that the head physician had been very much against the involvement of the CEC, fearing that the CEC would come to a conclusion they would disagree with, but still feel obligated to follow. Although CECs do not have a formal role in the decision-making process, one doctor expressed that the CEC's conclusion would be a directive for them. Another informant (number 7) pointed out that he thought a pediatric ward would be more careful with the complexity of an end-of-life decision, while other wards are not prepared to let CECs deal with decisions for which they actually have the formal responsibility. It is all about being master in one's own house.

Overall Experience

Twelve doctors had a positive experience of the CEC discussion, while three doctors reported negative experiences (Table 1). All three doctors described cases involving conflicts with relatives. The negative experiences were related to lack of systematic structure in the discussion, lack of ability to scrutinize the ethical problem or to add new perspectives, and that they had to wait too long before the CEC could discuss the case. In fact, several informants mentioned that there was too long of a wait before the CEC could arrange a meeting. The first critical informant (number 1) commented that

the CEC discussed the issue for a very short period of time compared to many informal discussions among the medical staff. The second critical informant (number 12) stated that some of the participants did not have much competence in penetrating ethical questions. The third critical informant (number 17) said that he had been thinking that the CEC might have disturbed the process.

The CEC's interdisciplinary composition, and its ability to scrutinize the ethical problem and discuss it systematically were emphasised as important for their positive experiences. One doctor (number 2) felt that the most positive part was the interdisciplinary aspect, to have the dilemma discussed by people outside an intensive care environment, and to see the case through the CEC's "eyes"—through their questions and considerations. Some informants mentioned that it was easier to reach a decision after the CEC discussion, some said that the CEC discussion made the decision-making process more well-founded, and some reported that they got moral and legal backing for their final decision. One informant (number 16) responded that the CEC discussion was an important contribution to the quality of their decision, and to the increased acceptance of the decision by the disagreeing minority within the medical team.

Discussion

Limitations

A qualitative approach has limitations as it presents information from a limited number of both doctors and committees. The use of a recorder may influence and limit the dialogue. The first author (a lawyer) had no formal or informal connection to a CEC during the data-collection period and most of the analysis-period, which is both a strength and a weakness. The second author (a doctor) has held national responsibility for the work of CECs for a number of years. This background may have led to a positive bias of her interpretations of the clinicians' evaluations.

As a lawyer, the interviewer was an "outsider" in a clinical context. This means that the interviewer might have overlooked or misinterpreted communication belonging to a medical culture. In addition, some of the doctors may have been uncomfortable talking to a lawyer about a difficult end-of-life decision. At the same time, it strengthened the study to have an interviewer with a profession other than medical, since a lawyer will look at the cases and the work of the committee with a different perspective than a health care professional. It is important to evaluate the work of ethics committees from different angles, especially when justifying the use of resources (Agich 2013; Kalager et al. 2011).

Discussing End-of-Life Decisions in a Clinical Ethics Committee: What is Material to Doctors?

Ethical, Legal and Communicational Support

The participating doctors shared different end-of-life decision stories with diverse complexity, involving both adult and minor patients. Nevertheless, all the

respondents have in common that they had an end-of-life decision discussed in a CEC. It is possible to compare their experiences, and recognize common features that tell something about the ability of CECs to offer relevant contributions to doctors who seek support in the analysis and solution of ethical dilemmas, independent of patient groups.

In all the interviews, the doctors mentioned ethical, legal and communicational challenges, which involved conflicts and disagreement about futility. The nature of ethical dilemmas probably remains relatively unchanged, as is pointed out in a review study of 255 clinical ethics consultations at a tertiary care academic medical centre in the United States. Issues of communication, family conflict, and futility continue to give rise to ethical quandaries, according to the study's conclusion (Swetz et al. 2007).

In the nine cases where the doctors were uncertain about what would be the ethically best solution, salient parts of their uncertainty was related to the patients being young, having small children, or uncertainty about the patient's preferences.

Conflict Management and Mediation

Six out of fifteen doctors involved CECs due to conflicts and communication difficulties between physicians and surrogates. In fact, in three of these cases lawyers were present in the discussion. However, it is likely that when lawyers are involved, the conflicts are already very serious, and may be at the point of no return. It is important that CECs get involved before the conflicts have developed too far (Førde and Hansen 2009; Førde 2008). In a previous Norwegian study of 43 health professionals who had a case discussed in a CEC, the doctors were the least satisfied with the CECs' ability to handle conflicts (Kalager et al. 2011).

In this study, the three doctors who had a negative evaluation of the CEC all had conflicts with the surrogates. We know that doctors seek ethics consultations in cases that involve conflicts (Førde and Vandvik 2005; DuVal et al. 2001). One pressing question is what a CEC can offer in a conflict situation, and how the committee should be staffed to be of use to clinicians when conflicts have developed around ethically challenging end-of-life decisions.

There are weighty arguments in favour of using CECs in conflict management and mediation, especially in difficult end-of-life decisions. First, conflicts between the medical team and the patients' relatives occur from time to time, and it would be beneficial if CECs could help to reach an acceptable resolution for all involved parties. In this case, the resolution would be found within the institution, and it is likely that this would reduce the conflict level compared to if the conflict was made judicial. This is, in most cases, preferable both in an economic context and for the involved parties. Petitioning a court to resolve a futility dispute may intensify the adversarial positions of the patient or his/her family and the hospital staff (Mickelsen et al. 2013). In addition, the Norwegian courts, according to a decision made in 2006 (court of first instance), and in 2007 (courts of appeal), seem to be reluctant to tackle complex end-of-life issues.[3]

[3] TBERG-2006-665 (court of first instance) and LG-2007-100482 (court of appeal).

Secondly, an ongoing conflict may result in burnout conditions, depressions and sick leave for both health personnel and the patients' next of kin. An American study of moral distress among all healthcare professionals found associations between moral distress and problematic end-of-life issues, and providing aggressive treatment only to prolong death (Whitehead et al. 2015). According to a descriptive pilot study using a survey design to explore nurses and physicians perspectives on caring for dying patients in intensive care units, the highest moral distress occurred in situations where caregivers felt pressured to continue groundless aggressive treatment (Hamric and Blackhall 2007). A descriptive study on moral distress in pediatric providers states that the most distressing situations include, first, continuing care which is not in the child's best interest, and, second, providing life-saving actions that only prolong death (Trotochaud et al. 2015). In our study, many relatives wished to continue aggressive treatment that the medical team found futile. One doctor involved in a conflict talked about "wear and tear phenomenon" and a dead end in the communication when he described a difficult long-term conflict with the parents of a minor. He emphasized the CEC's potential to solve a communication problem and prevent conflicts.

Thirdly, CECs offer the opportunity for all involved parties to listen to one another. In the court system, the principle of immediacy is fundamental, with good grounds. To see someone talk about their experiences and point of view, gives the listener a lot more information than reading a document the same person has written. It is easier to understand each other, to have a more correct interpretation of specific information, and to reach a common understanding of medical and other facts if all those involved are present at the same time. It is a way to avoid misunderstandings and a negative view of other involved parties. To utilize this possibility is demanding. Today, few Norwegian committees have patients and/or family members present during their discussion, and it is still a controversial issue among Norwegian committee members. The few who do report positive experiences (Førde and Hansen 2009). The problem of unbalance in clinical ethics consultations was pointed out more than a decade ago (Reiter-Theil 2003). Inviting patients or their families to participate during a CEC meeting reduces the risk of basing the discussion on unbalanced information (Førde and Linja 2015).

Fourthly, it will benefit the patient to obtain the right treatment level and to avoid unnecessary treatment. Finally, if CECs can be helpful in reaching a well-founded end-of-life-decision which both parties can accept, it may have positive financial consequences for the hospital and for society. CECs can support a structured decision-making process that could help save time and reduce stress according to a German study (Jansky et al. 2013). The conflict itself is costly both in terms of the time spent and the burden on the personnel. Futile treatment and legal conflicts both result in substantial expenses on different levels.

An Interdisciplinary Composition

A CECs' composition matters to doctors. Eight out of fifteen doctors mentioned that they expected a broader illumination that included having their case scrutinized by professionals outside the medical community. This requires an interdisciplinary

composition including professions outside the health professions. If CECs are to be helpful in achieving resolution when physicians and surrogates disagree, they must offer interdisciplinary communication and evaluation, including legal and ethical aspects, in their approach of the ethical problem. A patient representative, a lawyer and an ethicist are valuable as CEC members since they come from outside the institution and, thus, in high conflict cases may increase trust in the CEC's independence. A hospital chaplain may also complement the committee. In a review study of clinical ethics cases, 11 out of 17 unresolved end-of-life cases (of 203 cases) involved explicit religious claims (Brierley et al. 2013). A manual produced by the Centre for Medical Ethics (revised 2015) recommends that each committee should have external members.[4] The importance of involving both a legal practitioner and an ethicist is supported by an American study that found that health care professionals care more about a CECs' reconciliation of legal and ethical tensions, than a theoretical moral framework through which to resolve the dilemma (Marcus et al. 2015). It is also stated that moral distress can result from inconsistency between written values and norms and the actual practice and decisions of organizations, e.g., acting in the best interest of the patient, but being unwilling or unable to place the hospital at public risk when faced with controversial cases (Mickelsen et al. 2013). CECs can meet this inconsistency with a broad professional view when discussing a problem.

An interdisciplinary composition has many benefits. Nevertheless, it is a difficult aim, since limited health care budgets often lead institutions to rely on voluntary participation (Agich 2013). It may be a challenge to find committed health personnel, but an even greater challenge to include competent members from other professions outside the hospital. In addition, Norway, like many other countries in Europe, has to accept local CEC models due to geographical, economic and logistical considerations.

Thresholds

Some informants emphasized that today the thresholds are too high for involving CECs in actual cases. One possible explanation is a resistance among some doctors against arguments other than strictly medical ones, which follows with CECs. Another possible explanation is time pressure for doctors which may be an obstacle in contacting CECs. In addition, doctors seem to emphasize reaching consensus within the medical team (Bahus 2014). Involving CECs may be interpreted as having failed in this task. In end-of-life cases, professional norms often place the moral responsibility exclusively with the individual care provider (Mickelsen et al. 2013). It may be a sign of professional weakness to admit uncertainty and involve CECs for support.

Although formally a CECs' advice is solely guiding, our interviewees point out that it may be difficult for a doctor to decide against a committee's advice. Accordingly, it is important to realize a CEC's real power in contrast to the formal one. When going

[4] Manual for working in a Clinical Ethics Committee in secondary health services: http://www.med.uio.no/helsam/tjenester/kunnskap/etikk-helsetjenesten/manualer/manual_rev2015.pdf.

against clear advice from a CEC, the decision of the medical team can become legally vulnerable, especially if the conflict becomes judicial. One way of solving this is that CECs do not conclude with specific advice, but instead present all the arguments and values relevant to the different solutions in a complicated case. In our opinion, it is beneficial for CECs to give clear advice when the arguments support it.

Conclusion

Most Norwegian doctors who have used CECs to discuss end-of-life decisions find it useful. In end-of-life decisions, doctors may benefit from the support from a CEC when confronted with communicational, ethical and/or legal aspects related to uncertainty about the end-of-life decision. In conflict-cases, it is important to have sought CECs before the conflicts become too deep.

An important motivation for referring a case is to have the problem viewed from several angles. The need for legal and ethical knowledge and communication skills in ethically challenging end-of-life decision-making processes legitimates CECs as useful organs that add necessary competence.

In order to meet the doctors' expectations and need for support, CECs must be able to meet at short notice and to discuss the case systematically. An interdisciplinary composition is emphasized, and some of the CEC members should come from outside the institution to increase trust in the CEC's independence in conflict cases.

In the future, CECs need to demonstrate their crucial role in difficult ethical decisions to justify financial support needed to establish the necessary interdisciplinary composition and to accomplish their role.

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Compliance with ethical standards

Conflict of interest None.

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