

Novel paths to relevance: how clinical ethics committees promote ethical reflection

Morten Magelssen

Reidar Pedersen

Reidun Førde

Centre for Medical Ethics

Institute of Health and Society

University of Oslo

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Abstract

How may clinical ethics committees (CECs) inspire ethical reflection among healthcare professionals? How may they deal with organizational ethics issues? In recent years, Norwegian CECs have attempted different activities that stretch or go beyond the standard trio of education, consultation, and policy work. We studied the novel activities of Norwegian CECs by examining annual reports and interviewing CEC members. Through qualitative analysis we identified nine categories of novel CEC activities, which we describe by way of examples. In light of the findings we argue that some novel working methods may be well suited to promote ethical reflection among clinicians, and that the CEC may be a suitable venue for discussing issues of organizational ethics.

Introduction

The first clinical ethics committees (CEC) in Norwegian hospitals were established in 1996. In 2000, Parliament decided that all hospitals should have a CEC. The Centre for Medical Ethics (SME) at the University of Oslo has been given responsibility for competence development, evaluation of and research on the CECs (Førde and Pedersen 2012a; Førde et al. 2008; Førde and Pedersen 2011). There is a national mandate for the CECs (Norwegian Ministry of Health and Care Services 2011), and SME has developed a manual (Førde and Pedersen 2012b) and provides education for CEC members. The CECs produce annual reports that are presented on SME's web page. SME, then, has a central role in the Norwegian CEC system. Norwegian CECs are, relatively speaking, more homogenous in structure and function than CECs in many other countries. However, this has not prevented the CECs in developing their own preferred working methods and activities.

Traditionally, Norwegian CECs have, like their counterparts in other countries, performed the three standard functions of CECs: ethics education, case consultation, and contributions to the development and revision of hospital guidelines (Førde and Pedersen 2011). Typically, the education function has been served by seminars on clinical-ethical topics open to all hospital employees. Ethics consultations are typically performed by the full committee, and not handled by individual consultants or teams as in, e.g., the US.

US hospitals have been pioneering the development of CECs, but experiences have been somewhat mixed. CECs have been accused of being too remote from the daily activities of healthcare. Some have charged that US CECs exhibit "failure to thrive" because they are ill-equipped to handle the ethical challenges that are most pressing. Whereas CECs were designed to provide bedside consults, critics charge,

the crucial ethical issues at stake presently are rather general, structural, and organizational (Bayley 2006; McCrudden and Kuczewski 2006). Blake has contended that a "reinvented" healthcare ethics program should be, first, proactive to effect changes, not merely react to the cases that health professionals bring to the table; second, integrated in the organization, not isolated; third, accountable to measurable outcomes; and fourth, actively furthering the core values of the organization (Blake 2000). In response to this, the practices of "rounding" and "embedded ethics" are examples of attempts to integrate ethical reflection in daily clinical work (DeRenzo et al. 2006; Bruce et al. 2014); the "IntegratedEthics" model is an example of a system that addresses broader organizational issues (Fox et al. 2010).

Fox et al. identify several alleged shortcomings in the traditional CEC model, including insufficient integration in the healthcare organization, the lack of precisely defined goals, and a lack of commonly accepted quality standards. The "IntegratedEthics" model involves supplementing the traditional CEC with a separate organizational body, a "Preventive ethics group". The purpose of this group is "to produce measurable improvements in the organization's ethics practices by implementing systems-level changes that reduce disparities between current practices and best practices in the relevant area." (Fox et al. 2010, p. 16). In addition, the model proposes a third core function, "Ethical leadership", which involves improving the ethical environment and culture of the organization. Supplementing the CEC with additional bodies and initiatives is proposed as necessary for the ethics services to be integrated in the organization, comprehensive, proactive, and systems-oriented.

Norwegian CECs, too, are struggling to invent optimal working methods and to find appropriate roles in the organization. Although clinicians who have requested

a CEC consult typically describe the experience as useful, evaluations find that many CEC members and clinicians consider the CEC system to have little impact in the clinic and in the hospital organization (Førde and Pedersen 2011). Many Norwegian CECs, especially at medium and smaller sized hospitals, find that they receive rather few clinical cases. The perceived role of CECs may create barriers: some clinicians' impression of the CEC is as a 'court of law' that produces 'ethical verdicts' to submitted cases and on health professionals' conduct (Pedersen et al. 2009). Contrary to this caricature, the CECs perceive themselves as tasked with the mission of increasing the level of ethical reflection among healthcare professionals.

In the last few years in particular, many CECs have attempted different activities and working methods – activities that stretch or go beyond the standard threefold set mentioned at the outset. At SME's yearly national seminar for CEC members in November 2013, CECs were invited to share novel cases and tasks and detail how they were dealt with. This gave the impetus for a more comprehensive inquiry into the CECs' novel activities, the results of which is presented in this paper. We wanted to assess these activities that previously have not been explored systematically. In this paper we describe these various activities together with examples of CECs' efforts to inspire ethical reflection at all levels in the healthcare services.

Materials and methods

The main research question was, which activities do the CECs perform that go beyond the traditional tripartite classification? Furthermore, what characterizes these activities? What are the CECs' experiences with these activities; in particular, which factors promote or inhibit success?

The main source of information about CEC activities was the annual reports of the Norwegian CECs. A year's worth (2013) of annual reports from the Norwegian CECs, 31 in total, were examined, and detailed notes were developed. The notes were supplemented with information from SME's November 2013 national seminar for CEC members, in which CECs had specifically been invited to share experiences with novel cases and activities. In addition, cases with which we were personally familiar were added to the notes.

To supplement the information, including in cases where the annual report was felt not to give sufficient detail, the CEC representatives that had been most closely involved with the activity in question were contacted for supplemental telephone interviews. Seven CEC representatives were interviewed in total, about the details and rationale of their activities, the outcome, and factors contributing to the perceived success or failure of the activities. Notes were taken from the interviews.

The resulting data, i.e., the notes from these different sources, was then subjected to qualitative content analysis. The notes were read several times, before a categorization of the activities was attempted. This categorization was then revised and finalized by all three authors in conjunction.

Results

The CEC activities that did not fit the traditional tripartition, and that thus were considered as novel, were categorized and summarized under nine different headings. Below we present the most significant activities in further detail, with an emphasis on examples found to be particularly illustrative or interesting.

1. Seminars in the clinical departments subsequent to a CEC case consultation

Typically, a CEC case consultation ends with the preparation of the CEC's written report. The report is usually not disseminated beyond the clinicians directly involved in the case and the CEC referral. Sometimes, especially when the case highlights features that are particularly important for or recurring in the department in question, the case and the CEC's analysis may have considerable didactic potential and practical relevance. Some CECs have brought the case back to be presented in a seminar in the department. Salient aspects of the CEC's discussion are shared, and discussed further with the entire staff. This has enabled the CEC to educate staff about specific kinds of dilemmas, in addition to presenting tools for clinical-ethical deliberation and possible solutions.

For instance, one CEC was contacted by nurses who were unsure of the ethical appropriateness of a new treatment which, in their view, appeared not to benefit patients but merely prolong their dying process. The CEC requested a written submission detailing patient cases, cases which were then discussed in the committee with nurses and physicians from the department present. The case spurred the creation of a full-day seminar for all health professionals in the department. The seminar highlighted substantive ethical issues (e.g., how should potential benefits and burdens of the treatment be balanced?) and procedural ethical issues (e.g., how should the ward create room for ethical reflection in such cases? How can treatment-limiting decisions be made in a way that prevents moral stress and burnout among those who work in the closest proximity to patients and relatives? What should be done when there is disagreement within the team about the appropriate decisions?). In this way the CEC did not only educate about a recurring substantive ethical dilemma. The CEC also got to address potential shortcomings in the communication among professions,

and got to play a role in facilitating better dialogue and decision making processes in the department.

2. Tailored seminars for particular departments, wards or professional groups

Many CECs have also conducted seminars for departments, wards or professional groups that do not spring from recent CEC cases, but that attempt to tailor the discussion to the perceived need of the group in other ways. Typically, CEC members present the committee's work and example cases. Some CECs go beyond this more traditional way of educating clinicians. For instance, one medium-sized rehabilitation hospital designed a comprehensive seminar series in which CEC members also visited each interdisciplinary treatment team, discussing 1-2 cases brought forth by treatment team members. Some of these cases were presented and discussed in the final plenary session. Among several perceived benefits, the seminar series also informed the CEC about which ethical concerns were important for the clinicians. Often, CECs have noted an increased flow of regular cases from the departments visited in the aftermath of the visits.

3. Teaching and implementing programs for ethical deliberation skills

CECs have first-hand experience with the usefulness of systematic approaches to complex clinical-ethical cases. One CEC wanted to bring some of these deliberation skills out to clinicians in general. A committee member who was also an academic ethicist was particularly instrumental. The project was attempted in two versions; in the first and most comprehensive (in a neonatal intensive care unit (ICU)), an educational pamphlet and a one-page checklist as an aid for ethical deliberation were prepared, and staff were trained in plenary seminars and smaller groups. In the second

instance (a general ICU), reading material was scaled down to a single page and application was particularly focused on treatment-limiting decisions. In the first instance the checklist and procedures turned out to be utilized by few staff; whereas in the second instance the project was a relative success, seemingly having achieved its educational purpose and to some extent influencing staff deliberation processes (although this has not been assessed formally). CEC members responsible point to the scaled-down, second version as more feasible for busy clinicians; in addition, in the second instance the project had markedly stronger support from department heads. This was perceived as a prerequisite for the project's success.

4. Leading reflection groups in clinical wards

Several CECs have experiences with having members lead reflection groups on clinical wards. In one hospital in particular, reflection groups had been attempted at many clinical wards, and actively promoted by the hospital management as a way of promoting the hospital's core values. In other hospitals, the reflection group functioned mainly as a forum for "low threshold" systematic moral deliberation at the ward. Most group sessions would be chaired by a CEC member who would act as facilitator. Sessions would last 30-60 minutes, and would be held weekly or bi-weekly. Clinical-ethical issues would be raised by participants, and the facilitator would lead the discussion based on SME's six-step method for clinical-ethical deliberation (Førde and Pedersen 2012b). Most of the time patient cases would be discussed; sometimes, issues pertaining to organization ethics would be raised. Notably, among participants nurses were in the majority, whereas physicians were almost never present. The absence of physicians meant that crucial details about decisions and medical factors were not discussed. This was perceived to be a major

drawback for the discussion, which was still perceived as helpful in stimulating the ethical reflection of participants.

Heads of the wards would sometimes participate in the discussion. While this was thought to sometimes stifle free discussion, it was also perceived as helpful that leaders would get insight into ethical issues of importance to the clinicians.

Occasionally, cases would arise which would be brought to the CEC or to hospital management. However, many issues were resolved or dealt with adequately in the reflection group. In sum, reflection groups were therefore perceived as useful to strengthen the ethical reflection on the ward, and thought neither to stifle nor increase the flow of cases to the CEC.

5. Inviting wards to submit a case to CEC deliberation and participate in deliberation

In a bid to make themselves known and to initiate processes of reflection, some CECs, instead of waiting for referred cases, have invited wards and departments to contribute retrospective cases to regular CEC meetings, and to be present and participate in the deliberation. This is a way of getting to know departments and wards and the range of ethical issues that characterize these; if the experience is perceived as positive and useful by the staff, one consequence may be more future cases forthcoming for the CEC. Indeed, this has been a way for newly founded CECs to make themselves known.

6. Dealing with organization ethics

Increasingly, the CECs have treated issues of organization ethics. Initially, cases are discussed in the committee itself; however, CECs have sometimes dealt with cases that have turned out to involve matters of principle that, it is felt, ought to be dealt

with more generally, by a body with a broader mandate, responsibility and influence. Two CECs have referred such cases for the Norwegian National Council for priority and quality in health care, a body that in particular discusses new medication and medical technologies and advises on whether these ought to be implemented in the public healthcare system. These cases were initially presented to the CECs as cases related to treatment decisions for individual patients, but turned out to have significant general aspects. The first case was about an expensive new drug that could benefit a subset of cystic fibrosis patients. Should the costs be covered by public funds, as is customary in the Norwegian healthcare system? The CEC pointed out that, although treating these patients with the drug would make small inroads in the public budget, there is still the question of fairness when other patient groups may be denied costly treatment. The National Council discussed the case without concluding firmly, but stressed that the low prevalence of the disease in question should not in itself count in favour of prioritizing this group of patients.¹

The second case was about an expensive and poorly documented drug for a very rare neurological condition (Førde and Ruud Hansen 2014). The CEC stated that this particular treatment might involve an unfavourable cost-benefit ratio, and therefore advised that discontinuing the treatment could be defended ethically.

One CEC on their own initiative reviewed statements from the hospital board and initiated a critical discussion. The case considered a board statement in which it was stated that “The Board wishes the primary focus of the leaders to be to deliver on the financial requirements set”.² The CEC felt that the board’s emphasis was unsoundly imbalanced, emphasizing the keeping of tight budgets to the neglect of

¹ A report of the Council’s discussion can be found at <http://www.kvalitetogprioritering.no/saker/cf-legemiddel>

² Budstikka, May 3rd, 2013 (<http://www.budstikka.no/nyheter/frykter-kutt-pa-30-millioner-vil-ramme-pasientene-1.7872108>)

quality in the healthcare services offered to patients. The case was also picked up by a local newspaper, in which the CEC leader was quoted as stating:

We think it is important that [the hospital] is on economical balance, but it is disquieting that the board signals to patients and employees that it is the economy that shall be the main focus. ... A hospital board must never forget the first priority. That is the patients, and that is safe and good quality health services.³

Discussion with the hospital board ensued – including of whether the CEC had stepped out of its role in this case, as several board members pressed. However, the hospital board subsequently released a statement that “The board maintains as its primary focus the continued development of good, equitable and safe health services.”⁴

7. Bringing ethical perspectives to other stakeholders in the organization or health services.

Several CECs had members who also sat in the hospital trust’s committee for quality and ethics (alternatively, committees for quality and patient safety, or committees with corresponding functions). This arrangement promotes the visibility of the CEC among the hospital management. It may also bring a ‘CEC perspective’ to the discussion of general issues pertaining to quality and patient care.

Some CEC members who were also academic ethicists found that CEC work and cases had opened doors to cooperation with other stakeholders in the health

³ Ibid.

⁴ Ibid.

services. In one case, a CEC was contacted by a patient ombudsman who, based on a case of serious medical error leading to the death of a child, complained that the hospital lacked procedures for adequate care for patients and next of kin in such cases. As a result, the CEC was instrumental in developing new hospital procedures, with the patient ombudsman participating in the CEC's work.

Some CEC members also report that they have been appointed to government committees on healthcare law, based on their expertise in clinical ethics, an expertise which to a considerable extent has been built from experience with CEC work. For instance, one member (who was also an academic ethicist) of a CEC in a mental health institution was appointed to the government committee tasked with reforming mental health law pertaining to coercion; another CEC member and academic ethicist was appointed to two national commissions on priority setting in health care.

8. Dissemination of case reports

Several CECs have anonymized and adapted case reports, for publication on the hospital's intranet, or on SME's web page. SME keeps a collection of annotated CEC case reports to facilitate learning for CEC members and other interested clinicians.⁵ Some CECs have also published versions of their case reports as papers in academic journals (e.g., from previous years, Magelssen et al. 2012; Miljeteig et al. 2013; Larsen et al. 2013).

For instance, in one published case a female patient in her thirties with a serious progressive disease demanded that treatment be withdrawn, dying a few months later (Larsen et al. 2013). Health professionals who had treated her for years, but who were not responsible for the patient in her last months, feared that she had

⁵ See <http://www.med.uio.no/helsam/tjenester/kunnskap/etikk-helsetjenesten/kasuistikker/>

been influenced by depression, and questioned whether the decision had been sufficiently autonomous. A main dilemma was the balance between beneficence-based paternalism and autonomy. Should the patient's request have been granted? In the aftermath of the CEC deliberation, this led to the CEC conducting general discussions of issues relating to patient autonomy in the ward in question (as per activity #1 above), and subsequently to the published article which expands on the case report and draws on factors discussed within the department, bringing the discussion to the broader medical community.

CEC cases, and the deliberation procedure often utilized by the CECs, are often used when clinical ethics is taught to medical students at the universities of Bergen and Oslo.

9. Criticizing a clinical practice on the CEC's own initiative

Typically, a CEC discusses cases referred to the committee by clinicians. In some cases, however, CECs have themselves initiated discussions of clinical practices found to harbour ethical challenges. For instance, one CEC problematized ethical aspects of a clinical assessment tool used extensively in Norwegian psychiatric departments (Global Assessment of Functioning, GAF). The CEC questioned the present practice of 'scoring' the patient at every consultation and contact. Ethical concerns that were raised were, e.g., that scores, being highly value-laden characterizations of patient appearance and conduct, would be entered into charts and follow patients indefinitely; that scores typically would not influence treatment decisions; and that patients typically never were informed about the scoring. In addition, the CEC presented research and experiences that drew the validity and usefulness of the assessment tool into question. The CEC initiated discussion of the

practices in the ethical councils of several of the professions involved, obtaining the councils' written analyses of the ethical issues involved.

Factors facilitating or inhibiting success

In our interviews we asked the CEC members to reflect on factors that were perceived to either facilitate or inhibit the success of their activities. Informants operationalized 'success' as, in particular, improving the level of ethical reflection among clinicians. A subordinate goal was to spur further and improved contact between the CEC and the department or body in question.

Pertaining in particular to activities directed to other clinicians (activities #1-5 above), CEC members pointed to the following five factors as conducive to success: first, in order to go beyond 'classical' CEC tasks, members must have sufficient time. In medium- and small-sized hospitals especially, committee chairs may be expected to do CEC work on top of a full regular workload (Førde and Pedersen 2011). Part-time positions in the CEC may give the required room to build more extensive relations with clinical departments. In many of the novel activities, the involvement of CEC members who were professional ethicists was also central. Second, the attitudes of the heads of the departments in question were perceived to be vital. In order for a CEC activity directed to a department to succeed, department heads must both provide the required time for health professionals to participate, and must convey the attitude that ethics and the CEC activity are worthwhile. Third, sometimes activities must be tailor-made for a professional group. Several respondents stated that physicians were the professional group that were particularly hard to reach, but still very important to include in most case deliberations. The experience was that, in general, few physicians would turn up for CEC seminars unless the seminars were

given specifically for the physician group, e.g., by taking place within or replacing a regularly scheduled meeting. Fourth, for some activities, such as seminars or reflection groups, success to some extent hinges on the training, preparation, and personal abilities of the CEC members in charge. Finally, activities must not be too demanding or time-consuming; activities aspiring to inculcate skills and attitudes must lead clinicians to see how ethical deliberation may realistically be incorporated in their day-to-day work.

Discussion

Systematic clinical-ethical reflection in the Norwegian health services has been transformed in the last few decades. Initially this work started with the Council for Medical Ethics (est. 1962) of the Norwegian Medical Association. As mentioned, the first Norwegian CEC was established in 1996. From the Council's centralized, 'top-down' system, CECs have taken systematic clinical-ethical deliberation into the hospitals. Now, CECs are increasingly attempting to bring such deliberation to the clinicians themselves more directly, involving them in ethical reflection on problems closely related to their own practice, in the ways charted in this article.

Some of the practices detailed here are also novel in another respect, in bringing the CEC's ethical reflection 'outwards', to department heads, hospital administration, health professionals outside the hospital, to the general public, and to the national political arena. In these ways CECs have crossed traditional borders in two directions, bringing important questions of principle to the public and politicians, and bringing clinical-ethical reflection closer to the clinicians. Some cases may involve movement in both directions: for instance, a case about whether a particularly expensive drug should be offered may originate with a particular patient, and may

lead to CEC discussions that can both be of value to the local clinicians and other stakeholders, *and* may inform a general political debate about prioritization of scarce resources (i.e., activities #1 and 6 above).

Increasingly, Norwegian CECs are dealing with questions of organizational ethics. Whether CECs ought to handle such cases has been debated. Førde and Ruud Hansen analyzed 15 cases of general principle discussed in the CEC at the Norwegian National Hospital, and found that more often than not, CEC discussions had significant practical implications, such as revision of clinical or organizational guidelines, or debate on a national level (Førde and Ruud Hansen 2014). On this basis, the authors argued that the CEC is a suitable arena for discussion not only of cases pertaining to clinical dilemmas, but also of cases of general principle and organizational ethics. In the recent government green paper on priority setting in healthcare, CECs were singled out as suitable arenas for discussing cases involving priority setting (Norwegian Ministry of Health and Care Services 2014).

Still, it may be asked of each activity whether this is properly a job for a CEC, or whether this is an appropriate way for a CEC to work. It may be argued that a CEC, being mainly composed of clinicians, is ill-equipped to handle cases wherein clinical ethics and an individual patient is not the main focus. CEC members are typically not specifically trained in management or organizational ethics. Fox et al. claim that, in order to deal with organizational ethics efficiently and responsibly, the persons responsible should have expertise in areas such as principles for quality improvement and organizational change strategies (Fox et al. 2010, p. 19). These are skills not typically possessed by members of conventional CECs. Being embedded into the hospital culture, a CEC may also be prone to biases and conflicting loyalties when handling cases (Magelssen et al. 2013). For instance, in the last case referred in

the sixth category above, a critic may argue that the CEC, possessing neither the required insight nor authority, is in no position to criticize decisions made by the hospital board. Going outside its perceived area of competence and authority may weaken the CEC's credibility and perceived legitimacy in the organization. However, in this particular case the CEC was in a position to bring forth criticism that would be very hard to voice for individual clinicians.

Indeed, in our view CECs may in general have a vital role to play in providing an 'internal' – but still an open – systematic and critical review of the moral soundness of the clinical practices in the health services. The activities detailed show the CECs attempting to carry out such reviews, in addition to attempting to inspire clinicians to ethical reflection on their own clinical practices. The hospital management may already be interested in these aspects of quality improvement. However, the CEC may be particularly well suited to uncover and bring forth problematic aspects of the organization and the health care provided. A separate body of experts in organizational ethics would probably not have the same privileged access to clinicians' ethical concerns, and thus may struggle to uncover some of the pressing ethical challenges in the organization.

The ultimate goal of CEC work is to improve the quality of the health services; if an internal review and the corresponding critical reflection does not take place, quality may suffer. A lack of trust in the health services may lead to demands for external control, such as more fine-grained external 'top-down' regulation and laws that may come in its place; if the internal morality is perceived to be insufficient, external control and regulation may be called on. In our view, such developments may sometimes be unfortunate. If the CEC is to carry out internal reviews and foster the internal morality of health care services, they must be able to disseminate their

judgments and concerns both ‘inwards’ (to clinicians) and ‘outwards’ (to administrators, the public, and the political level). The traditional focus on case consultation may, unfortunately, lead to important insights being confined to an archived, written report, read only by the referring clinician. The CEC’s ethical reflection should sometimes reach a wider audience, as we have seen that in Norway it at times actually does. The present survey of the experiences of Norwegian CECs indicates that CECs may, despite a lack of specific expertise, deal adequately with some challenges pertaining to organization ethics.

A challenge for the CECs is to maintain quality when developing novel activities. Our hope is that continued inventiveness will highlight activities and working methods which can be refined and disseminated to other CECs. In this process it will also be important to assess the outcomes of these activities in a rigorous way (Schildmann and Vollmann 2010).

The present overview has shown the Norwegian CECs in action, trying and sometimes failing, driven by a wish to promote ethical reflection and the services of the CEC. The CECs may wish to inculcate a certain, reflective attitude to complicated medical decisions, beginning with the thought that ethical reflection matters for the health services to provide quality health care.

Potential limitations

Because the study relies on one year’s worth of CEC annual reports and the presentations at SME’s 2013 national seminar, we may not have discovered all significant CEC activities from recent years. The report of the consequences that the CEC activities have led to and the factors that facilitate or inhibit success, spring

chiefly from assessments made by CEC members who were themselves involved; our study does not involve any independent, rigorous evaluation of the activities.

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