Chapter in

Encyclopedia of Global Bioethics 2016 (Henk ten Have, editor)

Springer, Dordrecht

Clinical Ethics: Support

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Abstract

Clinical ethics support services (CESS) are services that aim at supporting health care professionals (including ancillary staff, managers and directors), patients and their families when being confronted with an ethical concern, question or dilemma. CESS is increasingly being implemented in USA, Canada, Europe and slowly also within other parts of the world. Delivery of CESS is often categorised broadly speaking into three different models : clinical ethics committees (CEC), individual ethics consultants (EC), and facilitation of moral case deliberation (MCD). Strengths and weaknesses of these three models are discussed. Furthermore, attention is being paid to the ongoing debate on quality and training of CES. Finally, this entry ends with a brief summary on the current developments concerning the evaluation of CESS, CESS outcomes and CESS's impact on quality of care.

Key words: clinical ethics, clinical ethics support, clinical ethics committees, ethics consultant, moral case deliberation, quality and training

Introduction

Clinical ethics support services (CESS) are services that aim at supporting health care professionals (including ancillary staff, managers and directors), patients and their families when being confronted with an ethical concern, question or dilemma. These ethical issues are often related to uncertainty or disagreement related to the definition of good patient care. However, some CESS also offer support for ethical issues concerning multidisciplinary team cooperation, prioritizing of limited financial sources, (human resource) management, institutional policies, etc. (this entry will not deal with research ethics committees such as: Institutional Review Boards). Delivery of clinical ethics support (CES) is often categorised broadly speaking into three different models: clinical ethics committees (CEC), individual ethics consultants (EC), and facilitation of moral case deliberation (MCD). One should not neglect the fact that there are also various kinds of *implicit* ways of giving or receiving support, such as education, team meetings, ethics guidelines, quality assurance protocols, etc. Furthermore, there are also ethics support services on the national level (e.g. a general or specific national ethics committee or advisory board). However, due to the limited scope of this chapter there will only be attention for explicit forms of CES within health care institutions.

In health care practice, there exists a huge variety in the way CES is organized and performed, both within and among these three models of services. Furthermore, CES can be offered out of different and sometimes even conflicting theoretical backgrounds. The normative status of the ethics support usually also differs (Pedersen et al, 2010); ranging, for example, from thinking along with those who asked for the ethics support, to giving advice, or to judging and sanctioning behaviour of health care professionals. CES staff, trainers in CES, researchers in CES and policy makers within the field of CES focus within their work on, among others things: the organisation and implementation of CESS, the practical and methodological use of CESS in health care institutions, the training of CES staff, the development of quality guidelines for CESS and the accreditation of CES staff, the development of new forms or combinations of CES, the evaluation of CESS itself and their impact on quality of care, moral competence of health care professionals and team cooperation. The interest in CESS is growing in both clinical practice, education and also evaluation science (especially in Western medicine). See for example the increase of CESS related papers in (clinical) ethics journals (such as: *Journal of Clinical Ethics*; *Clinical Ethics*; *Bioethics*; *Journal of Hospital Ethics*; *HEC Forum*; *BMC Medical Ethics*; *Bioethics, American Journal of Bioethics*; *Medicine, Health Care and Philosophy*; *Nursing Ethics*; *Journal of Medical Ethics*; *Bioethica Forum*; *Hastings Center Report*) and the interest for clinical ethics associations and/or conferences (such as: *American Society Bioethics & Humanities* (ASBH); *European Association for Centres of Medical Ethics* (EACME); *European Clinical Ethics Network* (ECEN); *International Conferences on Clinical Ethics and Consultation* (ICCEC); *International Association of Bioethics* (IAB)).

The aim of this entry is to give a brief introduction to the meaning and relevance of clinical ethics support in the USA, Canada and Europe, its various forms and methods, and some recent developments in research, training and quality assessment in CES.

1. Three models of explicit Clinical Ethics Support Services

Clinical ethics support services, though variously characterized, can roughly be defined as services to assist in the identification, analysis and resolution of value conflicts or moral uncertainties that emerge in health care practice (Aulisio, Arnold, & Youngner, 2000). Three well-known models of CES are: clinical ethics committees (CEC; including also 'ethics teams' or 'ethics working groups'), ethics consultants (either individual or as a small team), and facilitation of moral case deliberation (MCD). Though they first emerged in North America, CESS are now present within many health care institutions in Western medicine (Slowther et al, 1999). In this section three models of CESS and some specific characteristics of each model are being presented.

Clinical ethics committees

Clinical ethics committees (CECs), sometimes called hospital ethics committees, are the dominant form of clinical ethics support services in many countries, either as a standalone service or in conjunction with individual or small team ethics consultants (see below). Their development and integration within health care institutions have been driven either by a 'top down' legal or regulatory requirement (for example in the US and Norway) or by a 'bottom up' perceived need for support by clinicians (for example the UK, the Netherlands, Germany and Taiwan). Most CECs are in hospitals but there are an increasing number in nursing homes and community or primary care organisations (including institutions for mental health care and people with mental or intellectual disabilities). While there is some variation in committee membership and function both within and between health care systems that have CECs there are also several commonalities. Most CECs will include a range of health care professionals as well as lay members, one of their perceived strengths being the range of perspectives that can be brought to bear on the ethical issues the committee is asked to consider. Many CECs will seek to include a lawyer and/or an ethicist on the committee to provide specialized knowledge or skills in law and/or ethics and some CECs will co-opt subject specialists when considering specific clinical cases where the committee lacks knowledge of the particular clinical area. The question of whether a CEC should be required to have an ethicist and/or a lawyer as a member is a subject of debate.

Clinical ethics committees perform a range of functions within a health care organisation. Many have a primary role in providing a case consultation service (see below); most often this involves that those who request for ethics support participate within one of the regular ethics committee meetings. This is particularly true of CECs where there is no ethics consultant in the institution; hence where no consultants visit the ward. Other roles include advising on the ethical dimension of institutional policies and guidelines, the identity of the organisation, supporting management on ethical issues arising at an organisational level, and providing or facilitating education of staff on ethical issues. The level of integration and influence of the committee within the institution varies considerably. In some cases, the CEC is part of a wider programme of ethics integration within the organisation (such as the integrated ethics programme of the Veterans Health Administration in the US).

Strengths and weaknesses of the clinical ethic committees model

A potential weakness of CECs as a model of ethics support lies in their committee structure and hence their inability to respond rapidly and flexibly to requests for support in individual cases.

Concerns have also been raised about the ethical legitimacy of a committee whose members do not necessarily have training in ethics. However a potential strength is the diversity of experience and value perspective within a committee that can be brought to bear on the ethical dilemmas presented. The role of a CEC is almost universally advisory with the ultimate decision making authority and responsibility resting with the clinical team. This can result in a CEC being marginalised within the institution as it is seen as more of a forum for discussion than being integral to patient care. However, when a CEC is truly embedded in the institution, it can be seen as part of the multidisciplinary health care team, contributing a particular perspective to discussions about patient care.

Ethics consultants: individuals and small teams

Clinical ethics consultation, as a CESS, is a service provided by an individual or a small team to help to identify, analyse and resolve value conflicts or uncertainties that arise in specific clinical cases (Aulisio et al, 2000). Ethics consultation may be offered as part of the mission of a clinical ethics committee or as an independent ethics consult service (see above). Though commonly tied to ethics committees and most prevalent in hospital settings, independent ethics consultation services and even individual ethics consultants appear to be growing in other health care settings including skilled nursing and hospice (O'Brien, 2005). Issues that typically come to ethics consultation include end of life decisions, informed consent and decision capacity, confidentiality and privacy, the role of surrogates in decision making, and a variety of issues related to resource allocation and access to care (Aulisio et al., 2000). The number and types of ethics consultations varies tremendously from institution to institution with some services doing hundreds per year and others doing none at all (Fox et al, 2007).

Clinical ethics consultants are at the most general level simply those who perform or offer ethics consultation, i.e., those who staff consult services, in health care settings. As such, “ethics consultants” run the gamut from health care professionals with little or no formal training in clinical bioethics and whose primary responsibilities are elsewhere (i.e., in medicine, nursing, social work or another of the many allied health professions) but who may or may not have developed substantial expertise through years of engagement, to health professionals formally trained in clinical bioethics to non-health professionals with formal training in clinical bioethics, bioethics, or philosophical or theological ethics who may or may not have substantial familiarity with or experience in clinical settings.

"Clinical ethics consultant" or "clinical ethicist" is also used in the literature to refer to a subset of those discussed above, i.e., persons who may devote themselves part or full time to clinical bioethics activities as a primary activity (e.g., consultation, education, policy review/development). Typically, such persons have either formal training in clinical bioethics or a closely related area or they have taken on the role of “ethics consultant” or “ethicist” over time and acquired skills and knowledge through direct experience. Such persons may staff ethics consultation services and play other roles in a robust clinical ethics program, department or center. For example, clinical ethicists may attend rounds, develop area specific expertise (e.g., neuroethics), offer clinical ethics education for clinicians, students and the broader community, and contribute scholarship the research, presenting at conferences, and publishing articles or books. Though initially most common in major academic medical centers and teaching hospitals in North America, clinical ethicists appear to be increasingly

present in academic medical centers or teaching hospitals within health care institutions in Western medicine. In addition, clinical ethicists appear to be becoming more common, yet slowly, in clinical settings that are not closely tied to academic medicine.

Strengths and weaknesses of the ethics consultant model

Unlike the ethics committee model for CESS discussed above, the ethics consultant model has the advantage of being quickly responsive to need and adaptable to circumstances. For example, ethics consultants, whether as a small team or as individuals, can more readily meet with patients, family, and members of the care team when the need arises. They can also engage in multiple conversations with involved parties, following a case over a number of days if necessary, while also being present to units or floors as needed. In addition, to the extent that ethics consultants are formally trained in clinical bioethics and/or have developed clinic bioethics expertise through experience over the years, the ethics consultant model is closer to the type of specialty and subspecialty model expert model that is characteristic of clinical settings.

Unfortunately, some of the ethics consultant model's strengths also suggest its primary weaknesses. The responsiveness and adaptability of a small team or individual comes with the cost of affording fewer perspectives than are possible with full ethics committees. Similarly, by more closely conforming to the expert model characteristic of clinical settings, the ethics consultant model risks enabling clinicians to avoid ethical issues by "turfing" them to "ethics", rather developing a facility in engaging them directly . Such "turfing" also risks undermining the fact that health professionals, patients and family members are normally the primary moral decision makers – a fact taken very seriously for our next model for CESS, moral case deliberation, considered below.

Moral case deliberation

A moral case deliberation (MCD) consists of a group meeting with various participants who systematically reflect on one of their moral questions within a concrete clinical case from their practice (Molewijk et al, 2008). MCD is often understood as a joint moral inquiry into how to answer a specific moral question by means of reflecting upon each other's presuppositions, normative reasoning and the way participants reach a normative conclusion within the factual circumstances of the case. The (dis)connection between the facts of the case and the normative reasoning of the participants is an important analytical aspect of MCD. In MCD it is assumed that every participant has an equal possibility to reflect upon what is morally wise or good to do; hypothetical reasoning, hierarchical knowledge claims and expert knowledge claims are avoided as far as it concerns the moral answer to the moral question. A central aspect of MCD is creating a dialogue (instead of a discussion) since the epistemological assumption is that through the process a joint dialogue and constructive disagreement moral knowledge and wisdom evolves (Widdershoven & Molewijk, 2010).

Overall, the main focus concerns the central question: ''what should we consider as the morally right thing to do in this specific situation and how should we do it rightly?'' However, also more philosophical or conceptual questions are at stake (e.g. ''what is respect?'', ''what does understanding mean?'', "How much anger is allowed?") (Abma et al, 2009). Five central, often co-

existing, goals of moral case deliberation are: (1) to reflect on the case and to improve the quality of care within that case; (2) to reflect on what it means to be a good professional and to enhance professional's moral competencies, (3) to improve the multidisciplinary cooperation, (4) to develop, implement or adjust policies and guidelines, and (5) to support and enhance the institutional culture. Within MCD emotions may also play a role, although there specific function within MCD is to support the moral inquiry. The reflection, which often takes 45 min to 90 minutes, is facilitated by a trained facilitator (Stolper et al, 2015) and structured by means of a selected conversation method (e.g. the dilemma method, the Socratic Method). The facilitator, an ethicist or someone who is trained in clinical ethics and conversation methods, does not give substantial advice and does not morally justify or legitimize a specific decision. The expertise of the facilitator consists of, among other things, fostering a sincere and constructive dialogue among the participants, keeping an eye on the moral dimension of the case, supporting the joint reasoning process, and helping the group in planning actions in order to improve the quality of care.

MCD can be organised in several ways (e.g. as an ad hoc MCD meeting when there is an urgent request; as a single event during a team or policy building day; as one of the activities within a specific project; as a structural activity on the ward). MCD can also be used within a CEC or by a CEC.

Strengths and weaknesses of the moral case deliberation model

A strength of MCD as a model of CES is that all participants have and are given an equal say. Due to its strict focus on the methodology, participants not only learn to deal with a specific case but also learn to reflect together systematically and in a critical yet constructive manner. Furthermore, the moral responsibility stays within those who are confronted with the moral question since the MCD facilitator does not possess specific moral authority with the content of the case. Finally, MCD is often easily embedded within clinical practice. A potential risk of MCD as a model of CES is that participants merely focus on their individual reflections without taking into account the national, professional and institutional normative frameworks. Confusion about and a mismatch between the equal dialogue within MCD on the one hand and the hierarchical structure within the health care institution (including the formal decision-making responsibilities) at the other hand might also emerge. Finally, follow-up and possible policy implications at the institutional level of a single case discussion during a MCD need specific attention when MCD is offered.

2. Quality and training of CESS

There is an ongoing debate in the field of CESS concerning what constitutes quality of CESS and how to strive and control for quality of CESS. With respect to education and training for those involved in CESS, professionalization in some capacity would seem to be inevitable. The fact that CESS directly and indirectly impacts patient care and the health professional-patient relationship is itself a rather powerful driver of the need for professionalization. In general, the debate on quality of CESS can be divided in three sub-debates: a) should there be any quality assurance? b) When aiming at quality assurance of CESS, how should one approach 'quality'? (E.g. should a training program, a specific

CESS as such, or a single CESS staff member get accredited?), and c) What should be the consequences of negative quality assessments?

An example of the latter from the US has been suggested in a report from the ASBH Clinical Ethics Consultation Affairs Committee on "Certification, Accrediting and Credentialing of Clinical Ethics Consultants" (ASBH, 2010). They recommended development of a process for certifying the individual advanced practitioner "ethics consultant." More recently, the ASBH has published an 'aspirational' Ethics Code for ethics consultants (Tarzian et al, 2015). A more participatory and dialogical approach to quality assessment is coming from the Netherlands were CESS staff is developing various CESS quality guidelines (Molewijk et al, 2015). It is hard to imagine such a process not moving forward within both the US and Europe, even if only voluntary or aspirational in nature

As in the US, some European countries have developed a range of different training programmes, ranging from one day seminars to certificated course and modules in Masters Programmes, are available. An initiative at the European level came from the European Clinical Ethics Network (ECEN): they offered an 8-days ECEN Summer school in Clinical Ethics Support with various models of clinical ethics support (Italy, 2012). In a few countries, for example Norway, the training of clinical ethics committees is organised centrally at the Centre for Medical Ethics at the University of Oslo and supported by structural government funding. They do this by offering several annual educational conferences and courses, the dissemination of new insights from ethics and scientific research; by offering guidance (e.g. manuals, text books, tools/methods, etc.) and by means of policy development on the national level. This promotes consistency of quality standards across CECs. However in most European countries training is ad hoc with no national requirement or oversight of the training programme.

This raises questions about both the quality and impact of the training programs and, in the end, the quality of the service provided in individual institutions. In the UK, CECs have been criticised for a lack of consistency and transparency in relation to the quality of their work and their authority to provide advice on ethical dilemmas. This critique also applies to CESS outside the UK. Surveys of CESS in the US, Canada and the UK have found that less than half of members of CESS have had formal training or supervision from someone experienced in CESS (Slowther et al, 2012). The debate on quality standards and training for members of CESS raises the question of what counts as quality in this field, and in turn what are the goals of CESS. As it has been described in this chapter, CESS are diverse in both form and function. To determine if a particular service is providing a quality service one need to know what kind of service they aim to provide. Related to the debate on whether and how to assure quality of CESS, is the increased attention on (quality of) training programs for CESS staff. Internationally, there is a lack of accredited training programs for CESS staff. At the same time, there is a growing number of uncertified training programs being developed and offered.

3. Evaluation of CESS, CESS outcomes and its impact on quality of care

One way of paying attention to quality of CESS (and their staff) is by means of doing empirical evaluation research. CESS evaluation research is growing rapidly. In general, CESS evaluation research can be divided into three parts: a) the evaluation of the CESS itself (how is the service, its structure and its methodology evaluated?); b) the evaluation of the outcomes of CESS (e.g. what did

the requester learn from the CESS and in which way did it contribute to, for example, team cooperation and moral competence of the professionals); and c) the evaluation of the impact on, or the contribution to, the actual quality of care (e.g. in which way is the decision-making process and the involvement of patients improved?). Within evaluation research, both the research outcomes (i.e. the results of the research) and the research process itself provide ways of focusing explicitly on the quality of structure, process, content and impact of CESS (Schildmann et al, 2013).

Two general trends in the evaluation of CESS are identified: 1) the increasing range of and sophistication of outcomes used in evaluation research (compared to simple user satisfaction surveys prevalent in early evaluation studies); and 2) the increasing rigour of research design to include validated questionnaires studies (Svantesson et al, 2014) and long-term mixed methods follow-up studies. In addition to evaluation research other research themes in CESS include the role of emotions in CESS; the evaluation of the training of CESS staff; the implementation of CESS within health care institutions; and the participation of patients and relatives within CESS.

Conclusion

This chapter presented a brief description of clinical ethics support services (CESS) in the US and Europe. While CESS activities started in the 1970s in the USA, the last two decades CESS is evolving rapidly as a clinical practice and professional community within Europe as well. CESS related activities (such as journals, conferences, trainings, and evaluation research projects) seem to grow further every year. There are various forms for CESS and even within a specific form of CESS, there is a huge variety in how the CESS activity is performed. Along with the increased attention for CESS comes the discussion on defining quality of CESS staff, CESS activities and CESS training. Recent debates on developing standards for quality of CESS clearly demonstrate that there is no consensus on what that quality exactly is and how to develop or guarantee it. However, there seems to be a growing consensus that quality assurance is needed in the near future. Recently, CESS communities produced an ethics code for ethics consultants (ASBH) and a handbook on best practices and quality guidelines within CES (the Netherlands). In the meantime, recent initiatives for developing (inter)national CESS training programs and evaluation research focusing on evaluating quality, outcomes and CESS' impact on quality of care are alternative ways of developing quality of CESS. Finally, both international and national infrastructures for CESS and CESS staff (such as subsequently ASBH and ECEN, and the UK, Norway and the Netherlands) can play an important role in sharing experiences and further develop the professional quality of CESS and its actual contribution to the quality of care in clinical practice.

Conflict of interest statement

The authors hereby state that they do not have any conflict of interest.

Cross references

Applied Ethics
Applied Ethics
Bioethics: Clinical
Clinical Ethics: Accreditation
Clinical Ethics: Consultation
Clinical Ethics: Infrastructure
Clinical Ethics: Methods
Committees: Clinical Ethics Committees
Communication: Ethics
Consultation
Deliberation
Discourse Ethics
Hermeneutics
Medicine and Ethics
Organizational Ethics
Principlism
Professional Ethics

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