

The European Clinical Ethics Network (ECEN): the professional development of clinical ethics support in Europe and the importance of quality assessment through evaluation research

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This short contribution informs you about the founding and functioning of the European Clinical Ethics Network (including its recent products) with a specific focus on the evaluation of Clinical Ethics Consultation Services.

Clinical ethics support services

Clinical ethics support services (CESS) are services that aim to support health care professionals (including managers), patients and their families when 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. In addition to ethical questions related directly to the care of one patient some CESS also focus on ethical issues concerning multidisciplinary team cooperation, prioritizing of limited financial sources, (human resource) management, institutional policies, etc. In recent decades numerous structures have been developed to deliver clinical ethics support. *Clinical ethics committees* often meet regularly and can provide a forum for discussions of cases which have come up in the meantime [1, 2]. In addition clinical ethics committees take up other tasks such as teaching or the development of ethics guidelines. *Ethics consultants* (EC) are usually called by different stakeholders in clinical practice to provide support in case of ethical questions related to the ongoing care of a particular patient [3, 4]. 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 [5]. *Moral case deliberation* on ethical questions concerning a concrete case is a third form. The core of MCD consist of a group of the involved stakeholders within the case (e.g., health care professionals, patients and their relatives, managers, etc.) who have a moral inquiry by means of a dialogue into a central moral question connected to a concrete experience [6]. Usu-

ally a trained facilitator uses a specific conversation method in order to structure the dialogue and to keep the focus on the moral dimension of the deliberation and the case [7, 8]. In European health care practice, there exists a huge variety in the way CESS is organized and performed, both within and among these three models of services [9]. In the last few decades there has been an increase in the implementation of CESS structures in several European countries [10–13]. In parallel the training-, research-, publication- and conference-activities concerning CESS have grown [14].

The foundation of ECEN in 2005: its aims and its functioning

Following the second International Conference on Clinical Ethics Consultation (ICCEC) meeting in Basel in 2005, a group of European clinical ethicists founded the European Clinical Ethics Network (ECEN) in order to have more specific time for deliberating on developments in the various clinical ethics support services in Europe [15]. ECEN was an informal working group of clinical ethics scholars from European countries with both practical experience in developing and providing clinical ethics support services and research interest and experience in the field of CESS. At that time, the main goal of the network was to explore in detail how clinical ethics case support services are carried out in various European countries and to exchange experiences in order to learn from each other. Later, a second goal of the network became to foster and further professionalize CESS (e.g., by means of exchanging experiences with colleagues outside ECEN and by means of education and research). A third goal became to put CESS more on the European agenda, both in various health care domains and in training and scientific research.

The ECEN meets once or twice a year during a 1- or 2-day meeting, usually combined with the EACME (European Association of Centres of Medical Ethics) or

ICCEC (International Conference on Clinical Ethics Consultation) conferences. Each ECEN meeting consists of a number of clinical and research presentations, usually around a central topic (e.g., patient participation in CESS, CESS and the media, CESS and evaluation research, CESS and priority setting). Several working groups have been established with focus on specific topics and to report to ECEN later on their activities and results (see below: *ECEN related products*). The ECEN and the ECEN meetings are usually coordinated by the two ECEN founders (Véronique Fournier and Bert Molewijk) with help and support from the local host for the specific meeting. In order to share the coordinating activities, to make various ECEN policy issues more transparent and to foster the future development of ECEN, an ECEN Steering Group has been founded in 2012 (Pierre Boitte, Cristina Gavrilovici, Bert Molewijk (coordinator), Jan Schildmann, Anne Slowther).

At this moment the ECEN has 26 members from the following 16 European countries: Belgium, Bulgaria, Denmark, Great Britain, Croatia, France, Germany, Hungary, Italy, Moldavia, the Netherlands, Norway, Romania, Spain, Sweden, and Switzerland. To maintain its informal and workable structure, the ECEN is currently a closed network. However, members from European countries that are not yet 'represented'¹ can apply for an ECEN membership. In the following sections we will provide a brief overview on some activities and products of ECEN and propose future tasks that will stimulate (evaluation) work to assess the professional quality of CESS.

1. Facilitating exchange about the work of CESS within ECEN

One of the first products of ECEN was a joint paper in which we presented a descriptive evaluation tool for clinical ethics consultation. The background of this tool was our experience during the first ECEN meetings that there was no common language and structure to communicate the actual doing of CESS and associated theoretical and methodical aspects. Against this background key elements of CESS were defined and the framework of presenting CESS was developed as part of an iterative process of application and reflection. In its final version, the tool consists of 14 core questions addressing how a specific concrete case has been handled within a particular CESS [16]. For example: *What makes the case moral? What are the goals of this CESS? What kind of structure or method is used within this CESS? What is the normative status of the CESS activity? What are theoretical inspirations for the CESS? Is there any follow-up after the CESS?* Both the development and use of the descriptive evaluation tool

enabled the members of ECEN – within a relatively short time – to develop a common language to interpret what is done when doing CESS.

2. ECEN summer school

Given the need for education in CESS and the expertise of ECEN members a working group (Bert Molewijk, Renzo Pegoraro, Pierre Boitte, Andrea Dorries, Véronique Fournier, Marta Spranzi) developed a curriculum for a summer school in CESS which was held in Italy in 2012. The training encompassed the presentation of several methods and approaches to clinical ethics support. In addition comparative perspectives were presented, such as: the relationship between CESS and their core foundations (e.g., justification, normativity, ethics expertise), the identification of common reasons for and roles of CESS, and difficulties and resistances to develop or implement CESS. Furthermore, the summer school dealt with specific issues newly emerging in clinical practices (e.g., elderly patients, multiculturalism, role of patient and family in CESS). During eight days in the Italian Dolomites, 18 candidates from all over Europe and Indonesia received lectures and training in different CESS models from the members of the working group and various other ECEN members (i.e., Reidun Førde, Anne Slowther, Gerald Neitzke, Stella Reiter-Theil, Guy Widdershoven). There were also evening lectures from external guests on for example the role of emotions, law and religion in CESS. Based on the evaluations from the participants and the teachers a new program for an ECEN summer school on CESS is currently being developed. The next ECEN Summer-school on ethics support will get organized between Sunday the 27th of August until the 2nd of September 2017 (Dolomites, Italy). For information and subscription, please contact: Renzo.pegoraro@fondazioneanza.it.

3. Research and publications from ECEN

In addition to the above-mentioned publication on the grid to facilitate exchange on CESS two thematic issues have been published by working groups of ECEN. A thematic issue with five papers on *patient participation in CESS* was published in the journal *Clinical Ethics* (2009). Following an ECEN meeting on the topic, an ECEN working group (editors: Véronique Fournier, Reidun Førde, Ainsley Newson, Gerald Neitzke, Renzo Pegoraro, Stella Reiter-Theil) decided to describe their experiences and research in this area and the resulting thematic issue provided insights from France, Italy, Germany, Norway and the UK. A second thematic issue with seven papers on CESS in psychiatry (editors: Bert Molewijk and Stella Reiter-Theil) will be published in *Clinical Ethics* in 2016. This is the result of an ECEN working group which organized three semi-open ex-

1 Formally, the ECEN members do not represent their country.

pert-meetings and symposia on that topic in Basel (2013), Amsterdam (2014) and Oslo (2015). The papers will address various models of CESS in psychiatry, the specific ethical challenges it presents, and the organisation and structure of CESS in this clinical area.

4. Opening the network: ECEN Open Forum Days

In the last few years ECEN has discussed new approaches to stimulate more exchange with other European colleagues beyond the working group. One concrete result is the ECEN Open Forum Day which has taken place in 2014 (Lille) and 2015 (Cagliari). The Open Forum Day is open to people with experience in the practice, research and training of clinical ethics support. Among the aims are:

- to exchange and share ideas and experiences with colleagues who have experience in CESS or who are just about to implement or have already implemented CESS structures;
- to inform colleagues about ECEN and its work regarding clinical ethics support and services (CESS);
- to make CESS practices better known outside the ECEN network;
- to further develop the professional quality of CESS in Europe (e.g., by working together in training, research and clinical practice).

The 4th ECEN Open Forum Day will get organized on the 6th of September 2017 in Barcelona (prior to the EACME conference).

5. The importance of evaluation research for professional development and quality assessment

One topic at both the first and second Open Forum Day (2014 and 2015) and other recent activities by ECEN is the evaluation of CESS. CESS evaluation research has always been an important topic within the ECEN meetings and in addition there have been some smaller expert exchange meetings on evaluation of CESS (e.g., in Amsterdam and Bochum). Various ECEN colleagues were involved in the development of the European questionnaire on outcomes of moral case deliberation: the EURO-MCD questionnaire [17]. Currently the EURO-MCD questionnaire is being used in a multinational study (Norway, Sweden, France, the Netherlands) and a PhD project on the EURO-MCD is supervised by three ECEN members (Bert Molewijk, Mia Svantesson, Guy Widdershoven). Furthermore, a specific thematic issue on the evaluation of CESS will be held in Bioethics later this year (with three guest editors from ECEN: Bert Molewijk, Anne Slowther, Jan Schildmann).

While there are many, sometimes controversial, views on CESS evaluation research (e.g., why doing CESS evaluation research, what is a good outcome? What is the ethical quality of the outcome and how to determine that?) discussants share the view that evaluation (research) of CESS is an important way to contribute to the actual practice of CESS and to foster insights into how CESS could better function within the clinical context in which it is studied [1, 18–20]. As such, practically relevant evaluation research can be used to not only monitor the implementation and functioning of CESS, but also to contribute to facilitating its implementation and functioning [21]. Evaluation of CESS and at the same time involving the various stakeholders also contributes to a shared responsibility and ownership of the ethics support regarding ethical issues within clinical practice [22]. Evaluation research can also be of help when developing CESS quality standards or guidelines [23]. In designing CESS evaluation research, it is important to be sensitive and transparent to the normative dimension of both the research design and methodologies, as well as the choice for evaluation and outcomes parameters [20, 24]. Finally, CESS evaluation research can result in material which may improve the professionalization of CESS and which can be used for the training and education of current and future CESS staff.

Conclusion

The field of Clinical Ethics Support is a dynamic and moving field in which many professionals from various scientific disciplines are involved. CESS not only deals with very different challenging ethical themes in health care; it also deals with theoretical, normative and methodological challenges regarding *how* to deal with these ethical themes in an appropriate way. The latter aspect distinguishes CESS from the broader domain of Clinical Ethics. The attention and need for CESS, both in clinical contexts as in research contexts, is still growing. Within this domain and with the focus on ethics support, ECEN has developed from a small group of enthusiastic colleagues sharing their experiences of CESS to an expert group providing leadership and support in education, research and evaluation. ECEN continues to develop and support research and discourse on CESS and evaluation of CESS. ECEN provides a platform for exchange of both practical clinical cases of ethics support and national developments within Europe. It is developing professional viewpoints, testing out research ideas, and developing new collaborative research proposals. The annual ECEN Open Forum Days enable more exchange of interests, developments and expertise among CESS professionals on a broader European level.

For those who want more information about the next ECEN Open Forum Day, the ECEN summer school on CESS, or one of the CESS-related publications or ongoing CESS projects among the ECEN members, please contact one of the authors.

This contribution is based on the invited lecture at the ICCEC conference on the 21st of May 2015 in New York City given by Bert Molewijk: "Developments from the European Clinical Ethics Network (ECEN)".

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