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The development of a descriptive evaluation tool for clinical ethics case consultations

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Abstract

There is growing interest in clinical ethics. However, we still have sparse knowledge about what is actually going on in the everyday practice of clinical ethics consultations. This paper introduces a descriptive evaluation tool to present, discuss and compare how clinical ethics case consultations are actually carried out. The tool does not aim to define 'best practice'. Rather, it facilitates concrete comparisons and evaluative discussions of the role, function, procedures and ideals inherent in clinical ethics case consultation practices. The tool was developed during meetings of the European Clinical Ethics Network. Based on written reports and participation in the network meetings, the development and the content of the tool and the results of its application in presenting and discussing 10 case consultations are summarized. The tool facilitated understanding of the details of clinical ethics case consultations across individuals and institutions with various experiences and cultures, and comparison between various practices.

There is growing interest in the field of clinical ethics, and in particular clinical ethics consultation services in

Europe. Clinical ethics consultation services have been established in the USA, Canada, Australia, and in quite a few European countries over the last decades.^{1–13}

Clinical ethics consultation services may include policy development, education and consultations – performed by interdisciplinary committees, teams or single

The full list of members of the network are presented in Appendix 1.

Reidar Pedersen trained as a physician and philosopher, and has been employed by the Section for Medical Ethics, University of Oslo, as a research fellow and coordinator for the clinical ethics committees in Norway since 2004. In addition, he is working on a PhD project on the concept of empathy in medicine. His main research interests are clinical ethics consultations, patient autonomy, end of life decisions, clinical prioritizations and clinical communication.

Samia A Hurst is assistant professor of Bioethics at Geneva University's medical school in Switzerland, ethics consultant to the Geneva University Hospitals' clinical ethics committee, editor of the Swiss bioethics journal *Bioethica Forum* and president of the Swiss Society for Biomedical Ethics. Her research focuses on fairness in clinical practice and the protection of vulnerable persons.

Jan Schildmann is a researcher in medical ethics and a physician. After completing his clinical training in medical oncology and palliative care, he joined the Department of Medical Ethics and History of Medicine, Ruhr University Bochum, where he is leader of a research group on 'medical ethics at the end of life: norm and empiricism' 2010–2014 funded by the Ministry for Innovation, Science, Research and Technology of the German state of North Rhine-Westphalia. Dr Schildmann's areas of interest cover clinical ethics, methods and methodology in empirical medical ethics, research ethics and teaching, and evaluation of ethical and communication competences in medicine. His work has been in more than 30 peer-reviewed papers and several books.

Sandra Schuster is a registered nurse and psychotherapist, specializing in psycho-oncology. She works with patients with cancer in psychotherapeutic practice. From 2000 to 2005 she worked as a researcher at the Department for Medical and Health Ethics, Medical Faculty/University Hospital Basel, Switzerland. She is still an associated member of the department. Her main interest and activity in the field of medical ethics involves ethics consultation, developing training modules and teaching medical ethics for clinical staff. Until 2008 she was a trainer in the education programme 'ethics consultant in health care' (CEKIB, Hospital Nürnberg).

Bert (Albert Christiaan) Molewijk is assistant professor of moral deliberation and clinical ethics and works at the Department of Medical Humanities of the VU Medical Center in Amsterdam as programme director, Moral Deliberation and Clinical Ethics. He chairs a Health Ethics Committee in elderly care and is a member of a National Review Board for scientific research in mental health care. He co-founded the Dutch network for Clinical Moral Deliberation: 'Platform Moreel Beraad' (hosted by the Ministry of Health, Welfare and Sport) and the European Network for Clinical Moral Deliberation: ECEN (hosted at the VUMC). His main interests are methodology, practice and theory of moral deliberation, moral competence, clinical ethics, and empirical ethics.

ethics consultants.^{8,14} Consultations may deal with concrete cases involving an individual patient (henceforth 'clinical ethics case consultations'), or more general ethical challenges. Some ethicists prefer the terms 'moral deliberation', 'mediation' or 'facilitation' rather than 'ethics consultation'.^{15,16}

The literature on clinical ethics consultation services is still growing. However, we still lack practical and detailed knowledge about what is actually going on in the everyday practice of clinical ethics case consultations. (Although some publications delving into the everyday practice of clinical ethics consultations do exist.^{8,17–20})

Nevertheless, if one wants to develop clinical ethics consultation services, detailed analyses of existing practices are of vital importance.²¹ Thus, to foster such analyses, the European Clinical Ethics Network (ECEN) developed a descriptive evaluation tool for clinical ethics case consultations, in order to present, discuss and compare how clinical ethics case consultations are actually carried out (for information about ECEN, see Appendix 1).

The main purpose of this article is to describe this tool. The tool was developed through its application in presenting and discussing case consultations in ECEN meetings, and this application revealed some interesting results. Thus, this article first presents the development of the tool. We then present the content of this tool, the results of its application in the presentation and discussion of 10 clinical ethics case consultations from nine European countries. Finally, we discuss advantages and disadvantages of this tool, and discuss areas for further research.

The development of a descriptive evaluation tool for clinical ethics case consultations

At the first ECEN meeting (Paris, November 2005), some members presented a general overview of the clinical ethics services in their countries or academic institutions. During discussion, the network members agreed that presentations at the next meeting should include a case example from the presenters' own experience as an ethicist. The presenters were specifically asked to concentrate on the actual consultation processes, and only briefly summarize the content of the clinical case.

At the subsequent meeting (Maastricht, May 2006), it was still difficult to understand what colleagues were doing in practice. It became evident that there are multiple ways to analyse, describe and compare consultation processes. It also became clear that the ECEN members did not share the same language or concepts. For example, for some 'ethics consultation' implied an external expert giving substantial advice, while for others it meant facilitating moral dialogue. Therefore, some of the network members suggested developing a scheme or tool to facilitate exchange of practical experiences.

After agreeing on what the key elements of the previous presentations were, and how to label these elements,

an initial set of questions was formulated. The questions included concepts that were regarded as sufficiently clear and communicable. This resulted in a preliminary descriptive evaluation tool for clinical ethics case consultations. The second step was to discover which questions or elements regarding clinical ethics case consultation were still missing. The third step was to actually structure the presentations according to the questions in the tool. This third step, the application of the tool, continued during the next two ECEN meetings (Leuven, September 2006 and Lille, April 2007).

The tool was then used to structure the presentation of 10 clinical ethics case consultations. The presentations were given by 10 members from nine countries representing both western and eastern Europe (see Appendix 1). The presentations and the following discussions of the consultations and the tool were documented through handouts, meeting reports and individual notes made during the discussions following the presentations. This documentation has been analysed and summarized in this article by the five authors. Earlier drafts of this text were commented on by all ECEN members (see Appendix 1).

The tool and some results emerging from its application

The elements of the descriptive evaluation tool for clinical ethics case consultations – formulated as 14 questions – are presented in Table 1. This table also includes condensed examples of answers given to the tool's questions in the 10 presentations of clinical ethics case consultations.

In this section, we focus on some of the questions included in the tool, briefly describing their meaning and, where relevant, we also describe some interpretational difficulties identified when using the tool. Additionally, we present some interesting similarities and differences in the case consultations revealed through the application of the tool.

What makes the case moral?

Pinpointing the moral or ethical issues – and 'what makes the case moral' – is essential to understand what the consultation process is about. The answer to this question may also be relevant to decide whether the case should be processed by the ethics consultation service or not. However, the question leaves open who defines the ethical dimensions and how this is done.

Many ECEN members answered this question by pointing at the substantial topic (for example: 'What made this case moral was that it dealt with: the limits of patient autonomy, informed consent competency, euthanasia, etc.'). In other words, ECEN members did not answer the question by reflecting on (meta)analytical or theoretical criteria. In effect, the answers given presuppose some sort of preformed consensus about what is a moral or ethical issue and what is not and how to categorize clinical situations in ethical terms.

Table 1 Descriptive evaluation tool

Questions	Examples of answers given by ECEN members in the presentations
1. The matters at issue?	A psychiatric in-patient refusing to eat; withholding life-prolonging treatment; considerations of futility; euthanasia; competence assessment; disclosure of accidental genetic information about biological parenthood; how to handle disagreement or uncertainty.
2. Prospective versus retrospective?	Most of the cases were prospective; that is, a clinical decision was still to be made. Two out of 10 case consultations were done retrospectively.
3. What makes the case moral?	A 'classical' moral or ethical issue at stake (for example uncertainty about what ought to be done or the limits of patient autonomy), or that the clinicians experienced some sort of ethical challenge/unease, or referred the case to the ethics consultation service.
4. Goals of the consultation process?	Education and evaluation (for example explore 'if we did the right thing'); decision making support; providing protected space and time to voice ethical concerns; team building; improving the quality of care.
5. Structure or method?	Thorough description of relevant facts; balancing arguments; formulating the ethical question or problem; clarifying relevant norms and values; clarifying legal regulation; identifying alternative or acceptable options; evaluating the patient's quality of life; assessing responsibilities; identifying relevant practice; identifying the involved parties and their perspectives; focus on the possible viewpoints of those who are absent; input from relevant literature; formulating dilemma question in the form of 'A or B?'; clarifying the fact-value distinction; voting; looking for consensus; concluding, summing up; or coming to an ethical opinion to formulate advice.
6. Normative dimensions?	Listen and talk versus insist (see Box 1); procedural or communicative norms; action oriented norms; attitudinal norms.
7. Theoretical sources?	Principlism; narrative ethics; hermeneutics; phenomenology; clinical pragmatism; discourse ethics; Doucet's and Lery's steps of deliberation; casuistry; catholic tradition; professional ethics; eclectic pragmatism.
8. Legal status?	The consultations were not legally required and did not provide legally binding decisions.
9. Participants?	Interdisciplinary ethics committee or interdisciplinary teams; single consultant; the involved clinicians, clinical leadership; the patient; the relatives.
10. Information gathering?	Written submission; oral submission; more systematic interviews with the involved parties.
11. Documentation?	Written reports (anonymized); some did not make any written documentation.
12. Duration?	From one hour to three hours (only the group discussions; time for preparation/follow-up not included).
13. Place of discussion?	Conference room in the hospital outside the ward, or a conference room at the ward.
14. Consequences and follow-up?	Improve communication; consensus building; recommendation regarding treatment; procedural advice; investigation of successive cases; policy development; continued discussion at the ward; informal evaluation; publications.

Secondly, all of the presented cases included more than just one ethical issue and also more than one possible moral question. How then were the multiple ethical issues or questions determined? Often the ethics consultation service assisted the person who brought the case in formulating the ethical issues at stake. Some ECEN members considered the ethicists as experts in defining the ethical issues themselves, while others thought they should only facilitate or help the involved parties to define their ethical issues.

Structure or method of the case consultation

This element of the tool provides information about the procedures that were used explicitly to structure or facilitate the moral dialogue. The presentations often first gave a condensed description of 'ideal', 'general' or 'mostly used' method (see examples in Table 1), followed by an explanation of what was actually done in the particular consultation.

All presenters reported that some structure or method was used, and all the methods included a thorough description of the case or situation and relevant facts – in particular

the medical facts – and a discussion that included balancing and weighing arguments. The methods were used more or less explicitly (for example some use a method providing some general points that are introduced during the discussion; others use methods with written steps in succession). Sometimes the method was modified, for example due to the characteristics of the case, the level of conflict or time limits. The reported methods did not presuppose any particular moral theory (for example deontology or virtue ethics).

There were some interesting variations in the methods presented. For example, two of the clinical ethics case consultations included voting on the possible solutions and only a few explicitly included identification of the involved parties and their perspectives. This does not imply that these aspects were totally absent in the other consultations, but different aspects seem to be emphasized to various degrees.

Some members pointed out that the meaning of the terms 'method' or 'structure' in relation to ethics consultation is far from self-evident, and that most of the questions included in the tool could – at least in principle – be described as methodological aspects of ethics consultation.

However, relatively narrow concepts of ethics consultation ‘method’ seem to have developed in the literature and in practice. For example, how to submit a case or involve participants was not generally considered part of the consultation method.

Normative dimensions of ethics consultation

All case presenters were asked to specify how they had addressed normative dimensions of the ethics consultation process using a 10-point ‘inventory of activities dealing with the normative dimension in Clinical Ethics Consultation’²³ (see Box 1). The inventory covers a wide range of activities referring to various theoretical frameworks.²⁴ Most of the consultations presented by the ECEN members included only normative activities between level 1 (listen, talk) and level 7 (apply, elaborate). Applying the inventory to the cases revealed that many of the presenters preferred to focus on the process or on procedural norms and they were generally reluctant to give specific and substantial advice.

Several of the network members stressed that the issue of normativity needs further elaboration. The inventory’s focus is primarily on various levels of directiveness used in the consultation, while other ways to analyse morality are not highlighted. For example, the inventory does not offer distinctions between procedural norms (for example, include the patients or relatives in the moral dialogue), action-oriented norms (for example, do not kill) and attitudinal norms or virtues (for example, empathy or practical wisdom).

Participants in ethics consultation

In general, an interdisciplinary ethics committee or interdisciplinary team (3–20 people; for example nurse, physician, ethicist, hospital chaplain) performed or provided the clinical ethics case consultation. In two instances, a single ethics consultant performed the consultation. The involved clinicians (for example physicians and nurses treating the patient) participated in all the consultations, while the hospital’s clinical leadership participated in two consultations. Patients or relatives only participated in two of the consultations, and in one of those only in the second of two

consultation meetings. In one other instance, the patient or relatives were informed afterwards about the consultation.

Some comments on the tool and the various practices

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 clinical ethics case consultations. This is quite remarkable, given the various international and cultural backgrounds of the ECEN members and the variety of theoretical and practical expertise. For example, some European countries are just starting to enter the field of ‘clinical ethics’ – and even the term ‘clinical ethics’ is unfamiliar for many. At the same time, some European countries have university institutes which train clinical ethicists. Thus, the descriptive evaluation tool seems to be applicable in countries and institutions with various expertise, experience and culture.

The tool and the use of single cases seemed to be an important condition for mutual comprehension. By making use of the tool, the presentations of the ECEN members became more concrete, explicit, and thereby transparent and comparable. The questions in the tool encouraged both ‘naïve’ and fundamental questions like ‘What do you actually mean/do when...’ or ‘Why did you do it this way?’

A possible disadvantage of using this kind of tool is that its structure can restrain presentations as well as discussions. The tool, however, did prove very valuable in addressing its two ultimate goals: understanding the details and practicalities of single clinical ethics case consultations, and starting an exploratory comparison of various clinical ethics case consultations. To foster constructive critique and shared understanding, and to be able to be creative in a group, some common ground and structure are needed, and here the tool proved fruitful. The tool may arguably also have made it easier to address additional points that were not included in the tool (for example, organizational aspects of clinical ethics services, such as institutionalization, funding, impartiality, the professional environment and the role of power, culture and religion, as well as who brought the case to the committee) by allowing discussions to cover more ground in a shorter time frame. (For some suggestions on how to frame discussions about organization of clinical ethics consultations practices, see e.g. Fox *et al.*²⁵.)

The 10 clinical ethics case consultations subjected to the tool were presented by individual members of ECEN, who described one single case consultation performed in their institution. Thus, the descriptions and examples given in this paper cannot claim to be representative of the members’ practices, institutions or countries. However, we believe that the information gathered revealed some interesting similarities and differences in the clinical ethics case consultations studied.

Box 1 Inventory of activities dealing with the normative dimension in clinical ethics consultation²³

- (1) Listen, talk; try to understand; search ethics focus.
- (2) Clarify, ask questions; specify ethics focus.
- (3) Interpret, evaluate; change perspectives.
- (4) Analyse, argue, compare pros and cons.
- (5) Refer to, rely on values/norms.
- (6) Articulate problems (that are overlooked, neglected) or errors.
- (7) Apply, elaborate, conclude.
- (8) Suggest, recommend; respond to ethics focus.
- (9) Advocate, defend arguments, values or principles.
- (10) Insist on or resist against decisions or errors.

For example, the way patients, relatives and clinical leadership are involved in the consultation process varied and there were diverging opinions about who ought to participate. What appropriate patient inclusion in ethics consultation might look like has been the object of some discussion, and the question is very far from being resolved.^{15,26–30} The appropriate inclusion of relatives and clinical leadership in clinical ethics consultations also merit further exploration; indeed, this has now been further explored by some of the ECEN members, something which has resulted in several publications on the role of patients in European clinical ethics consultations.^{31–36}

Only one of the 10 consultations presented was systematically evaluated. One reason for the rarity of evaluation was an acknowledged lack of goal definition prior to clinical ethics case consultation. This understandably makes both evaluation and establishing links between the goals and actual results of clinical ethics case consultations difficult.

The application of the tool and the resulting discussions also highlighted some important theoretical and empirical questions, for example what is the ethical content of clinical ethics case consultations and what makes a case moral? And, who decides whether a case brought to an ethical consultations service includes an ethical issue or not? In some situations ethical challenges are defined as medico-scientific issues, often implying that it is the physician who ought to make the decision. In other instances, clinical ethics is made too central or all-encompassing, and thus may blur other aspects of the case – for example, diagnostic, prognostic, legal, economic or organizational challenges. The question about what makes a case moral is important. It can help to decide whether the case – or certain aspects of the case – is suitable for clinical ethics consultation. It can also serve analytic and discursive purposes and help to focus and structure the discussion in a fruitful way. Moreover, the answers to this question may indicate what ethics consultants and clinicians regard morality to be about and to explore what values are at stake.

Summing up

The development of the descriptive evaluation tool illustrates a fundamental point: in order to understand each others' complex practices one needs both details of concrete examples and a sufficiently clear conceptual base to analyse, describe and discuss that specific example. The tool provides a tentative start to facilitate more practically oriented and detailed discussion, evaluation and eventually research on clinical ethics case consultation, without losing sight of normative content and ethical theory.

The tool does not attempt to define 'best practice'; rather it facilitates concrete comparisons and evaluative discussions. Used in network meetings including participants with diverse experiences and practices, the tool proved effective to challenge the participants to critically

think through their own practices and identify possible areas of improvement.

We invite others to apply the tool, and modify, specify or add questions. We hope that this paper may stimulate further discussion about how to analyse, present and evaluate the practice of clinical ethics case consultations, and lead to a further exchange of experiences.

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Appendix 1: The European Clinical Ethics Network

Following the International Conference on Clinical Ethics Consultation meeting in Basel in 2005, a group of European clinical ethicists founded the European Clinical Ethics Network (ECEN) in order to learn from each other and thus help to foster clinical ethics in Europe. ECEN is an informal working group of clinical ethics scholars from European countries with practical experience in developing and providing clinical ethics services as well as a research interest in this field (ECEN members are listed below). A first goal of the network

was to explore in detail how clinical ethics case consultations are carried out in practice.²²

ECEN members (2005–2008)

- Francesc Abel, *Institut Borja de Bioètica, Universitat Ramon Llull, Barcelona, Spain*
- Silviya Aleksandrova, *University of Pleven, Bulgaria*
- Lazare Benaroyo, *Université de Lausanne, Département inter-facultaire d'éthique, Switzerland*
- Pierre Boitte, *Centre d'éthique médicale, Université Catholique, Lille, France*
- Ana Borovečki*, *Andrija Stampar' School of Public Health, School of Medicine, University of Zagreb, Croatia*
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- Bert Molewijk*, *Maastricht University, Health Ethics and Philosophy, The Netherlands*
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*ECEN members who presented clinical ethics case consultations.