EACME Newsletter

European Association of Centres of Medical Ethics

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SPECIAL ISSUE ON CLINICAL ETHICS - Number 40 – August 2015

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EDITORIAL

Dear Colleagues and Friends,

You are currently holding the latest newsletter of EACME in your hands, this time as a special edition on the topic CLINICAL ETHICS - DEBATES, TRENDS AND CHALLENGES. We chose this topic mainly for two reasons. This is, on the one hand, due to this year's EACME conference in Sardinia, which is dedicated to exactly this topic (Sept 17-19, see: http://www.eacme2015.org). On the other hand, the discipline and practice of clinical ethics is becoming more and more professionalized and with this development, questions about implementation, quality assurance, and evaluation ensue. Unsurprisingly, this was also the topic of the International Conference on Clinical Ethics Consultation held in New York City this spring.

For these reasons, we invited you to contribute short manuscripts, e.g. on your experience about the status quo of clinical ethics evaluation in your respective countries. We are delighted that our invitation was so well received. This reaction shows that clinical ethics is still growing and gaining momentum in many European countries, despite some tough challenges that still need to be overcome. In some European countries, clinical ethics is still nascent or lacking at all, in others there are many clinical ethics committees or services, but their activities are marginal and they are not coordinated in a professional way. On this background, this special issue presents reassuring examples of coordinating and professionalizing clinical ethics, e.g. in the Netherlands and Italy. In order to ensure high-quality ethics consultation in health care facilities, the German Academy of Ethics in Medicine has recently introduced a program of certification that enables clinical ethicists to apply for three levels of certificates

based on the experience (ethics consultant, ethics coordinator, clinical ethics trainer).

Clinical ethics is also moving to areas that urgently need ethics support but have so far been neglected. Contributions in this special issue present innovative ideas and models how to implement ethics consultation in small hospitals, (medical) social facilities or the outpatient primary care setting. These are still pioneering works, but they underscore that ethics support is being increasingly valued and respected across diverse health care situations.

We would like to thank all the authors who have contributed articles to this special issue: Pierre Boitte and Jean Philipp Cobbaut (Lille, France), Andrea Dörries (Hannover, Germany), Jean Martin (Geneva, Switzerland), Federico Nicoli (Varese, Italy), Janine de Snoo-Trimp, Mia Svantesson and Bert Molewijk (Amsterdam, the Netherlands), Sandra Thiersch (Munich, Germany), Froukje Weidema (Amsterdam, the Netherlands) and Michael Dunn (Oxford, United Kingdom).

Last but not least we would like to draw your attention to the "Letter of the President" by Chris Gastmans. Chris will finish his presidency in September after more than 13 years of active work for the Executive Bureau of the EACME (first as secretary-general, then as treasurer and finally as president). For the daily work of EACME this certainly means a huge loss. At the same time, we gladly look back on everything we could learn from him in the past years and are thankful for all the positive developments and ideas he has brought in for the continued existence of our society. We would like to thank him cordially, on behalf of the entire editorial team.

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LETTER OF THE PRESIDENT

Since my mandate as president of EACME has come to an end, this will be my last letter to you as president. A new Bureau will be established at the annual EACME meeting in Cagliari. My time as a member of the Bureau of EACME – first as secretary-general (2002-2010), then as treasurer (2010-2013) and finally as president (2013-2015) – fills me with gratitude toward so many colleagues who shared my enthusiasm for the promotion of European perspectives on bioethics. First and foremost I wish to mention my predecessors, Guy Widdershoven and Renzo Pegoraro, who – both in their own way – made a valuable contribution to the flourishing of EACME. The organization of the annual EACME conferences has grown out to be one of the most stabilizing factors of EACME during the last ten years. The EACME conferences are known among bioethicists for their friendly atmosphere as well as for the opportunities they provide to young scholars to present their work on the international scene of academic and professional ethicists. The conference on clinical ethics in the magnificent city of Cagliari exemplify on the openness of EACME to young promising centres who are working hard to establish health care ethics not only as an academic discipline, but also as a driving force for more person-centredness in clinical care practices. As this thematic issue of the Newsletter is dedicated to clinical ethics, it can be considered as a perfect introduction to the conference on clinical ethics in Cagliari.

Furthermore I wish to express my thankfulness to the colleagues of the bureau of EACME – Rouven Porz and Ruud ter Meulen – and to our executive secretary Angelique Heijnen who are all willing to continue their efforts to develop EACME as a platform for academic dialogue and networking. The EACME prize, the EACME Scholarship Exchange Programme, the EACME Newsletter and the weekly EACME News messages are – besides the annual conferences – efficient tools to be used by young and older ethicists to develop relationships with colleagues from other universities and countries and to acquire the necessary experience in networking. I invite all members of EACME – and especially the members of the Board of Directors – to stay in close contact with the new Bureau to be established in Cagliari, in order to guarantee the input of new and fresh ideas for the further development of EACME. An important accomplishment of the Bureau during the last year was the re-establishment of EACME – after consultation of the Board of Directors – as an international Foundation, based in the Netherlands, with a stable legal structure. We had to succeed with this major administrative procedure within a sharp timeline in order to avoid huge administrative problems that could hinder the further flourishing of EACME on the long run.

The good news is that this re-establishment of EACME as an international foundation has had no impact on the basic organizational structure and the daily functioning of EACME.

My last and most personal thanks go to Paul Schotsmans, one of the founding fathers of EACME, who will be given emeritus status at a celebration event in Leuven on September 25 2015. His unbridled enthusiasm in spreading the EACME vision has inspired many generations of European bioethicists. In 2016, EACME will celebrate its 30th anniversary. On September 8-10 September 2016, the Centre for Biomedical Ethics and Law of the University of Leuven will host the annual EACME conference. The preparations for this great anniversary conference are already ongoing and will be broached throughout the coming issues of the EACME Newsletter. But first, we hope to meet you all in Cagliari on the beautiful island of Sardinia.

Chris Gastmans
President

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OUTPATIENT ETHICS CONSULTATION: NEEDS OF SEEKING ADVICE PERSONS

Due to the increasing technological progress of medicine, doctors and patients are increasingly confronted with ethical issues (e.g. decisions on the end of life). Over the last 20 years, ethics committees were founded in German clinical institutions to assist doctors, nurses and patients as well as their relatives in dealing with these issues. The implementation of clinical ethics committees has made progress. However, there are hardly any consultation services for the outpatient area until now. On the 111. Ärztetag in Germany (2008), the relevance of an outpatient ethics consultation was recognized. The Ärztetag has recommended to establish outpatient ethics consultations. Four years later, a young team of 21 persons decided to offer an outpatient ethics consultation in Bavaria, Germany. The founder of this committee was Dr. Birgit Krause-Michel (www.netzwerk-hospiz.de).

What is an outpatient ethics consultation?
In 2012, an outpatient ethics consultation was established in Bavaria. At the moment, 21 persons from different professional groups participate (e.g. family doctors, doctors, nurses, jurists, pastors and social service). Per annum, there have been 25 consultations. The outpatient ethics consultation is conceived as a process model (maximum of 3 consultants per session). Family doctors, nursing homes, social services, person in charge and family members are the target group. Consultations are carried out on the spot (e.g. nursing home). During the last two years, different models (e.g. the Nijmwegener Model as well as the Maltese Model) were used to structure the case deliberations. At the moment, the ethics consultants use the "Prinzipienorientierte Fallberatung" created by Prof. Georg Marckmann. Besides the case deliberations, the outpatient ethics consultation also offers further educations for its own members as well as for family doctors and nursing staff.

Our research project
In 2013 the founder decided to evaluate the Outpatient Ethics Consultation regarding at the development and improvement of the consultation. From August 2013 to July 2014 an evaluation study was performed. We did three interviews with experts (the founder of the Outpatient Ethics Consultation as well as two facilitators), 19 interviews with the members of the consultation and 10 interviews with seeking advice persons. From November 2014 to March 2015 a questionnaire study with family doctors was performed. We sent about 175 questionnaires by post and by email. A total of 58 family doctors answered.

Interview Study of Seeking Advice Persons
In 2014, an interview study with 10 seeking advice persons was performed. 9 of these persons were family members who requested an ethics consultation for their husband or siblings. One person was a person in charge. The recruiting of the sample was made by the ethics consultants. That's the reason why it was very easy to find persons for the interview study. The people were very excited and talked a lot. The interviews lasted about 60 minutes. I asked many questions about the following topics:
- Patient's diseases
- Needs of seeking advice persons
- Expectations of seeking advice persons concerning the ethics consultation
- Their feelings during case deliberation
- Improvement of the Outpatient Ethics Consultation
- Evaluation of the ethics consultants' work

The people loved to talk about these issues. That's the reason why I got a lot of interesting answers about the following topics:
- Ethics consultation and ethics consultant
- Patient's life and course of disease
- Family members' life and suffering
- Health care system in Germany

In this article, I want to present some interesting answers to the following questions:

• What needs do seeking advice persons have?
• Which expectations do they have?

Needs of Seeking Advice Persons
Some seeking advice people told me that it was not easy to call the ethics consultants. On the one side, they didn't know the offer of the Outpatient Ethics Consultation. And on the other side, they were unsure if these people could really help them. But after the first talk, the seeking advice people were really happy because the ethics consultants could support them at the following topics:
• medical support
• legal support
• monitoring/follow-up-care for themselves

People often told me that it was not easy to understand the doctors. The patients were taken care of more than one doctor. And the different physicians told different opinions about the patients' diseases to the family members. That's the reason why it was difficult for them "to make the right decision" (e.g. should they really agree to another surgery? Should they finish life-sustaining measures?). The ethics consultants helped them to understand the opinions and to find a good decision.

Another point was the legal support. People often told me that the patient's advanced directive was ignored by doctors, nurses and even themselves because they were unsure if the advanced directive is correct. Therefore, the participation of lawyers was important during the first talk and the case deliberation. They could explain to the seeking advice people if the advance directive is correct.

One or two weeks after the case deliberation, the ethics consultant called the seeking advice person. The consultant asked how the person feels and if the person needs some help (e.g. counselling). If the person wants a counselling the ethic consultant will organize it. People told me that this follow-up care was very important for them because they could talk about their feelings and other important aspects.

Expectations of seeking advice persons
I also asked the persons about their expectations in relation to the ethics consultants. Most people told me that they need support especially in medical and legal matters. Another important aspect was the ethics consultant's personality. The seeking advice persons told me that they needed a person who could do factual statements. They didn't want an emotional consultant. They even expected a consultant who could make decisions. From their point of view, an ethics consultant should organize and coordinate the case deliberation. But the consultants should also give some advice during the conversation (e.g. should we

finish life-sustaining measures?). The interviewed persons told me that the advice was very important for them.

Conclusion:
The results of this interview study are very interesting. As a conclusion, I can say that
• there is definitely a need for an ethics consultation in the outpatient area.
• family members are more interested in medical and legal support than in the solution of ethical problems.
• a follow-up care is important for family members as well as for nurses and for family doctors. This is a special offer of the Outpatient Ethics Consultation which seeking advice people really need.

I would be glad about some comments and/or experiences from other studies in the outpatient area. If you want to discuss the results or if you need more information about the project, please contact me:

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CLINICAL ETHICS INTERVENTIONS IN MEDICAL SOCIAL ORGANISATIONS: TOWARDS AN INSTITUTIONAL INTEGRATION OF THE ETHICAL APPROACH

We would like to point out here that thanks to the clinical ethics analyses conducted with institutional professionals and managers, the approaches initiated in medical social institutions have revealed the institutional dimension of the ethical questioning in a relatively specific way.

Context: Ethical approaches and medical social institutions in France

Over the recent years our centre has been more and more often consulted by medical social facilities in search of a support with the ethical treatments they are confronted with as they accommodate and accompany vulnerable people.
In France, social and medical social services and facilities represent the whole of the institutions working for the support and accompaniment of vulnerable people, whether children, old-age people, disabled people or persons in precarious situations, under the aegis of a framework act entitled "Loi de rénovation de

l'action sociale et médico-sociale" [social and medical-social action remodelling act]. This act aims at promoting people's empowerment and protection, social cohesion, citizenship practice as well as preventing exclusion and addressing its effects (art. L. 116-1).

This bill (passed on January. 2, 2002 and contemporary to the 4-March-2002 law related to patients' rights) founds the intervention of professionals and institutions not only on the respect for people's dignity, integrity, privacy, intimacy and safety but also on the possibility for the users to exercise their rights and fundamental freedoms by participating in the design and implementation of an individualized accommodating and accompanying project.

Thus, as it is highlighted by ANESM's[1] recommendation concerning the ethical questioning in social and social medical facilities, the growing interest in ethics in those institutions is related to both the vulnerability of the accommodated or accompanied populations and a complex mission entrusted by the community to professionals and institutions. This mission is subjected to an inevitable tension between attentiveness to persons and the public good as well as to the evolutionary aspect of social and medical social work due to technological evolutions in particular.

In this context, a clarification of the ethical stake of practices seems to be made necessary as a result of three concerns: the reassertion of the accompanied persons' – i.e. residents' - actor position, the professionals' need for landmarks in front of the contradictions between the various purposes of social action in accompanying situations and, eventually, the articulation between the personal, professional and institutional ethical components[2] required for a consistent action.

Challenge: to integrate an ethical approach into the components of an action context

The ethical challenges related to practices have eventually been confirmed by the ethical reflection work conducted with three institutions working in the disability sector. Indeed, these institutions wanted to work on situations in which they had had to face sensitive concerns when trying to combine challenges related to the respect for the individual and a compliance with the rules aiming at a collective

interest. The matter was, for instance, to be respectful of the users' freedom to move around while ensuring everyone's safety. It might also be a matter of being respectful of ways of living and private life while ensuring an adequate common living.

A reflection conducted on what the actions taken in parallel with those institutions shows the need for an integrative ethical approach, the hypothesis of which we produced in an issue of *Journal International de Bioéthique*[3] entitled *"*De l'éthique clinique à l'éthique institutionnelle" [*From clinical ethics to institutional ethics"*. As a matter of fact, according to us, practicing a so-called contextual clinical ethics implies an evolution allowing the integration of the ethical approach into the action context components determining behaviours based on culture, organizational modes and the structure of the organisation. This integrative aim requires a contextual, pragmatist and reflexive approach in which clinical ethics helps comprehend the specific context, and be attentive to the matter of actors' interactions, identities and roles, as well as of the way these interactions vary according to the structure of the organization within which they occur.

One operator of this integration: the risk-management issue

The intermingling of situations with actors' interactions and the organisation appears quite clearly through the three experiments conducted recently - or still underway - related in this paper. As a matter of fact, the clinical ethics analyses typically focus on risky or problematical behaviour management issues as well as on situations at risk. For instance, a 62-year-old lady, recently suffering from cognitive impairment, running away ten to fifteen times a day, strolling about just for the sake of strolling about… or a brain-injured couple's sexual and emotional life disturbing the institution's togetherness. In this type of situations, people's appreciations vary according to their positions within the institution. For example, a healthcare manager will naturally stick to a vision that is consistent with institutional responsibilities while being attentive to everyone's role in front of the risk, whereas a psychologist will be more attentive to the risk considered through the resident's personality.

Approaching these ethical matters through the risk issue results in some sort of a "disintegration" of the issue or of the ethical dilemma and brings it to light through the prism of the institution's various actors. Indeed, focusing on the risks created by the life within those medical social institutions seems to lead the ethical exercise to characterizing the matters of roles

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[1] L'Agence Nationale de l'Evaluation et de la qualité des établissements et services sociaux et Médico-Sociaux [The National agency for the assessment of the quality of social and medical-social facilities and services], including the Recommendation about an ethical questioning in medical-social facilities and services, June 2010, consulted on 15 July 2015 - http://www.anesm.sante.gouv.fr/IMG/pdf/reco_ethique_anesm.pdf
[2] *Ibidem*, p. 7.

[3] P. Boitte & J.-P. Cobbaut, « Vers une gouvernance réflexive de la démarche éthique dans les institutions de soin », *Journal International de Bioéthique*, vol. 3-4, Dec. 2012, p. 23-24.

and of the coordination between the actors in presence rather than pointing out the influence of culture and organizational modes.

One consequence of the orientation taken by clinical ethics approaches: a methodological destabilization.

Such a dynamics brings out a series of questions from the point of view of the construction of the ethical approach and, singularly, from the point of view of clinical ethics practices and methodology. It sets the question of the way the ethical stake should be characterized. In this context, do we stick to a perspective consisting in fuelling a debate between ethical positions? What is the result expected within the scope of an ethical approach if the point is just to make a decision? What evolution of the ethical approach tools – particularly of the analysis grids - is implied by this dynamics? How to become capable of working on these questions with the actors concerned? What new tools do we need to approach the mode to be used to deal with those situations or the relevant intervention modes? How to improve the ethical approach to acknowledge the fact that the management of those questions is related to culture, to the organization and to its structure and normative context?

Useful signs to answer those questions will probably be brought out when fully assuming the perspective of an institutional change in the ethical approach and in the integrative vision within the institution.

Perspective: towards an institutional change in the clinical ethics approach

From the emergence of the institutional dimension of the ethical intervention, one of the major characteristics of the ethical approach becomes to enable an articulation between the actors' questioning about particular situations and what we could call the setting-up of a new professional responsibility related to an institutional frame allowing a reflexive and collaborative work.

In that respect, it may be interesting to highlight the various ways of accounting for institutional stakes along with the actions conducted.

As a first scenario, the action conducted proceeded from the will to rely on an ethical approach, and more particularly on a clinical ethics approach, in order to work on questions and situations allowing to rework on the facility's development project. The clinical ethics approach is used to analyse emblematic situations producing cross-disciplinary or horizontal questions (sexuality and emotional life; the institution as a residence; life project…). The preselection by the institutional managers (senior executive manager, healthcare managers) of themes that are illustrated by

the situations being discussed restricts the group's learning capacity. As a matter of fact, the group cannot improve their approach from what they have been talking or thinking about, particularly because there is a preselection of the themes and situations approached. The process leaders feel this lack and, in order to further their clinical ethics work, ask for a supplementary reflexive work helping to get a better articulation of the clinical ethics approach with the institution's quest for solutions to the problems that have been raised.

As a second scenario, the approach has been integrated straight away into a configuration open to some institutional structuring, namely by including field professionals, voluntary managers and institution leaders in a steering committee but making a primary distinction between the different types of groups, whether clinical, thematic or steering. In this type of configuration, the institutional structuring of the ethical approach overrode the clinical ethics approach. As a consequence, little was taught from the contextual analysis allowed by the work conducted on clinical situations to build up an inductive institutional approach that would be more adequately adapted to the institution's specific activity by allowing to support and to take advantage of the clinical ethics approaches.

As a third scenario, the ethical approach is conducted by the managing team, the senior and junior managers. On the basis of the in-depth analysis of an emblematic risk-management situation within the medical social facility, this approach helps point out more institutional stakes related to the background culture of the institution (empowerment of disabled people and the greatest possible respect for their freedom) but also the professionals' organizational modes, up to the internal and public (professional and voluntary) governance structure of the two institutions referred to here. The group was committed into a work both on the characterization of the ethical stakes induced by risk-taking situations and on the governance mode at the various levels of the association involved in this reflection on risk.

A few provisory lessons

From these three experiments, we may draw a few provisory lessons.

The first one is that professionals and institutions are willing to work on the ethical aspect of their practices from clinical situations. This work helps get a better collective comprehension of the ethical stakes and of the context inducing them, by pointing out the institutional stakes implied as these problems come to light. The notion of risk appears as a pivotal one between situations and the more organizational stakes of professional practices within those institutions. It is an invitation to a reflexive approach helping

characterize the ethical challenges at stake and to build / sharpen the tools making this work possible.

The second lesson is that it seems to be fundamental to make sure a collective learning and reflexive governance dynamics are at the heart of these approaches if the promise to be kept is to create an articulation between the clinical ethics work, the acknowledgement of the ethical approach by the institution and the perspective consisting in inducing changes in the running modes of the institution according to the problems it comes across. From this point of view, a pragmatist characterization of the ethical questioning seems to be the condition for an integration of the ethical approach into the organization.

The third lesson is that it seems to be important to be able to spark the participants' reflexivity on the ethical processes conducted together in order for a productive articulation to be created between the clinical work, the reconnaissance of the organizational stakes and the governance of - i.e. the orientation given to - the ethical approach.

The fourth lesson is that the point is to determine different levels of interventions and intervention strategies in order to get to an inductive clinical ethics-based construction of the reflections conducted concerning the policy to be implemented in the field of risk-management, referring to the example involved here.

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EVALUATING MORAL CASE DELIBERATION (MCD) BY MEASURING PERCEIVED OUTCOMES – THE DEVELOPMENT AND VALIDATING OF THE EURO-MCD INSTRUMENT. AN EUROPEAN STUDY

Clinical Ethics Support (CES) can take many forms. One of them is Moral Case Deliberation (MCD), which is increasingly being used within European clinical ethics support services. MCD is a structured dialogue among various stakeholders (such as health care professionals, health care providers, patients and their family/friends, etc.) led by a trained MCD facilitator, about a pressing moral question that arises from a concrete experience. The main aim of MCD is to support the involved stakeholders in dealing with the moral questions and thereby improving the quality of care and the cooperation. However, it is unknown whether and if so, how, this aim is reached. There have been some evaluation studies on MCD, but their focus was often on how participants experienced the MCDs *themselves* (Weidema et al. 2013; Van der Dam et al. 2011; Molewijk et al. 2008a/b; Svantesson et al. 2008a/b; Førde et al. 2008; Janssens et al 2014). Insight in the actual *outcomes* of MCD is highly needed, especially because of the expanding demand for implementation of MCD in health care, education and other non-profit domains (such as police, justice, health inspectorate, contra-terrorism).

EURO MCD Instrument
Therefore, an instrument was developed to measure the perceived importance and experiences of participants on the outcomes of MCD – the EUROMCD [Svantesson et al. 2014]. The instrument includes 26 pre-defined outcomes covering 6 domains of MCD: 1) Enhanced collaboration; 2) Enhanced emotional support; 3) Improved moral reflectivity; 4) Improved moral attitude; 5) Impact on organizational level and 6) Concrete results. Health care professionals are asked to fill in a questionnaire before they participate in a MCD to measure their preferred outcomes of MCD at baseline, and to complete a second and third questionnaire after participating in 4 and 8 MCDs respectively. By this, their preferences and experiences regarding various outcomes of MCDs as well as their eventual development in appreciating these outcomes are assessed.

Information about what MCD participants prefer and experience gives insight in the impact of MCD on the daily clinical practice of health care providers, like work climate and communication. This might indirectly contribute to the quality of care. Because these MCD outcomes are 'experiential phenomena', the perspectives of participants are highly valuable (Svantesson et al. 2014). The instrument is unique in its flexibility and sensitivity for the context. Since the goals of a MCD are not always clear before a series of MCDs has started and might even change during the actual series of MCDs, measuring the perspectives of participants gives room for this potential change and development while still assessing the final outcomes of the MCDs. Insight in the extent to which certain outcomes are experienced and appreciated, can contribute to the further development of MCD itself in general (as a form of CES). Furthermore, it can support the implementation of MCD in a specific context as the instrument might be used to adjust MCD to the needs of MCD participants in a specific setting. Finally, measuring the MCD outcomes after participating within a series of 4 MCDs and 8 MCDs will entail information on the short and long term outcomes of MCD, which has not been studied yet.

Current status

The first version of the instrument has now been developed and partly validated using a Delphi expert panel with European experts and content validity testing with various representatives of the target population (Svantesson et al. 2014). We are currently in the phase of using the EURO-MCD in various countries and making an European database. The present project also aims to further psychometrically develop a reliable and easy applicable instrument to measure outcomes of MCD – the EUROMCD II, flexible to apply in various settings. This is being done by testing the instrument in the actual field: in various health care domains within various European countries and with different kind of health care professionals. By this, the results of the current and future instrument may deliver important evaluative data of the various outcomes of MCD in general and the differences of experienced and perceived outcomes among various countries and health care professionals in Europe.

Currently, France, Norway, Sweden and The Netherlands are involved in the study. The project is 'work in progress' and thereby open for other countries who want to evaluate the use of MCD as a form of CES within their country. If you want to take part, or to get more information about this project, be welcome! Feel free to contact the project coordinator via euromcd@vumc.nl. We hope to submit the first papers of the current validation project by the end of this year.

Janine de Snoo-Trimp (PhD candidate), Guy Widdershoven (supervisor), Mia Svantesson (co-project leader EURO-MCD & co-supervisor); Bert Molewijk (co-project leader & supervisor)

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ETHIQUE CLINIQUE: L'IMPORTANCE D' ÊTRE NON AUTORITAIRE

«Dans le dialogue national sur la formation et la certification des consultants en éthique clinique (CEC), la demande est universelle pour améliorer leurs connaissances et compétences. Il est largement admis que beaucoup d'entre eux ne sont pas adéquatement formés.» C'est le début d'un article du *Hastings Center Report,* par la directrice du Programme de médiation en éthique clinique de l'Université de Pennsylvanie (1). Qui poursuit: «il y a un consensus clair qu'une attitude 'autoritaire' doit être évitée dans le conseil éthique - à savoir, éviter une approche où le professionnel impose ses priorités éthiques ou ses convictions religieuses à l'ensemble des 'stakeholders' (personnes concernées) dans une situation complexe ou conflictuelle.»

Pourtant, dit Fiester, bien peu a été fait jusqu'ici pour former ces professionnels à ne pas imposer leurs valeurs. «Une étape essentielle est d'identifier ce qui est ses convictions personnelles, voire ses souhaits normatifs, dans le contexte de la diversité des positions, en soi justifiables mais contrastées, qu'on trouve dans le pluralisme propre aux Etats-Unis. Evaluer sa propre position parmi d'autres points de vue légitimes fait prendre du recul par rapport à des engagements moraux qu'on peut personnellement juger absolu ou universels» (alors qu'ils ne le sont pas pour d'autres). Il paraît clair que, dans les pays européens dont les fondements philosophiques et juridiques sont comparables, le même avertissement est valable.

L'article de Fiester décrit un «Bioethical Positions Inventory», comprenant quinze paires d'affirmations

sur des questions éthiques (dans chaque paire, une attitude «conservatrice» et une «libérale»). Les professionnels en formation font d'abord un diagnostic de leur propre position sur chaque question puis, dans un second temps, leur tâche est de préparer une argumentation défendant la position à laquelle ils sont opposés ! (cet exercice les protège de s'en remettre à une discutable «hégémonie des valeurs» - Fiester).

On leur demande aussi de discuter une expérience vécue, selon les étapes suivantes: 1) Décrivez une consultation où une position à laquelle vous êtes profondément attaché était en opposition directe avec celle du patient, cas échéant de la famille ou d'autres soignants; comment alors avez-vous conduit la discussion; 2) Décrivez un cas où vous avez été préoccupés de réaliser que vous orientiez la consultation pour aligner son résultat avec vos valeurs à vous? Avez-vous fait quelque chose pour corriger cela?; 3) Décrivez un cas où une des personnes concernées a eu de la peine à s'exprimer et donner sa position morale. Quelle a été votre stratégie pour « « amplifier » et articuler son opinion devant le groupe ? Ce faisant, comment avez-vous maintenu votre propre neutralité quant aux valeurs en cause?

De telles démarches pédagogiques sont pertinentes et nécessaires. En 2012, l'Académie suisse des sciences médicales (www.samw.ch), dans sa recommandation «Soutien éthique en médecine» et à propos de l'attitude fondamentale des membres d'une structure d'éthique, dit entre autres: «faire preuve d'introspection sur leurs propres choix de valeur; être prêts à reconsidérer leur avis initial à la lumière d'une discussion commune, [notamment] avec des personnes de points de vue différents; être ouverts aux autres disciplines et professions; être prêts à acquérir une vision réaliste du quotidien clinique.»

Cela étant, la mise en œuvre d'une pratique de sélection et de formation de membres de commissions d'éthique en accord avec ce qui précède n'est certainement pas simple (sans même parler ici d'évaluation/supervision ultérieure. Fiester encore: «Les organisations nationales de bioéthique ont émis des avertissements à propos du risque d'imposition de leurs valeurs par les consultants en éthique, mais le problème est trop insidieux pour être amélioré par de simples directives.» Oui, on est ici dans un domaine qui ne se laisse guère gérer par des règlements et est plus du registre des attitudes professionnelles, relationnelles, déontologiques. C'est plus par la réflexion et l'échange interdisciplinaire approfondi sur des situations difficiles qu'on peut promouvoir une culture non-autoritaire en éthique. L'auteure parle de « capacité de bien écouter et de montrer à l'autre (aux autres) intérêt, respect, soutien et empathie». Il convient d'avoir ces enjeux à l'esprit, dans le travail au sein de commissions d'éthique comme dans la pratique quotidienne.

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1.Fiester A. Teaching Nonauthoritarian Clinical Ethics : Using an Inventory of Bioethical Positions. Hastings Center Report 2015 (March-April), 45, No. 2, 20-26.

NB: Cet article parle de la situation aux USA, où souvent les CEC ne sont pas médecins. Toutefois, l'argumentation développée vaut pour toutes celles et ceux qui sont engagés dans la consultation éthique clinique (on reconnaît dans nos pays aussi que le conseil éthique ne peut/doit pas être un «monopole» médical).

CLINICAL ETHICS SERVICES (CES) IN SMALL HOSPITALS IN GERMANY

When training members of clinical ethics services (CES) in our Hannover qualification programme or in in-house seminars, I often observe that small hospitals (100 – 300 beds; about a third of all German hospitals) have considerable problems with running a CES, and that common, well-known problems with CES in big hospitals (among others too few ethics consultations, reluctance of staff, lack of time) become more obvious. These problems result in non-sustainability of CES, lack of qualifications for ethics consultants, and an absence of networking.

What are the reasons?

In Germany, the situation in hospitals can presently be characterized by a shortage of staff and an economic pressure creating - especially in small rural hospitals - a strong competition for "survival". This leads to two results: on the one hand hospital managers actively implement CES with a strong tendency to publicity reasons and media coverage ("We have to have a CES in order to be known as an excellent hospital"). On the other hand the hospital managers try to refrain from distributing adequate financial resources to their CES for training, leave of work and substitutes, part-time positions or networking ("We just cannot afford it"; "Substitution has to be organised within the department"). CESs implemented only for publicity campaigns usually do not function in the long run, because staff become well aware of this and do not show enough commitment. CESs without financial resources cannot function because they lack training and qualification - and consequently competence in clinical ethics. All these aspects and the respective

problems arising seem to be aggravated in small (rural) hospitals.

Classical ethics committees usually provide ethics case discussions on wards with an impact on clinical ethics decision-making. However, some wards do not call their CES because staff do not consider it necessary or because they are not aware of its advantages. In these circumstances a clinical ethicist (fulltime or part-time) can actively seek contact and try to build up trust for implementing ethics case discussions. As clinical ethicists are usually not available in small hospitals, the impact of CES cannot be built up and CESs almost certainly gradually decline with members resigning. Thus, ethical conflicts may even aggravate due to personal controversies within healthcare professionals.

Furthermore, if there is no clinical ethicist available, members of CES, most often healthcare staff such as physicians or nurses, have to perform CES tasks or qualify during their usual routine work or as an aditional work, sometimes without financial compensation. As there already is a staff shortage beforehand, this is a considerable disadvantage und disproportionality when compared with larger hospitals.

And last but not least, it proves to be more difficult to build up networks with other CES when they are scattered over a region and not situated in a larger town.

So what are the options for small hospitals?

Concerning sustainability:
One - though presently barely realistic - solution for small hospitals may be to qualify at least two to three persons in clinical ethics, and provide leave for them from usual clinical work for some hours a month to work as ethicists for an inhouse CES, and especially enact ethics case discussions. Another solution may be to introduce special ethics rounds on e.g. intensive or oncological wards and organised by members of CES. Ethics rounds may consist of members of the usual physicians' rounds, additionally including members of CES (f.e. once a week). Ethics rounds can also be special meetings by ward staff and CES members to discuss individual patients which present moral problems. Experience shows that ethics rounds lead to a more structured decision-making process, competence and satisfaction among staff, patients and their relatives.

Another approach can be to use already existing organisational structures for communication about moral problems. For instance, most hospitals have mortality or oncological conferences for imminent cases where physicians (and sometimes nurses and other health care professionals) meet regularly to discuss procedures for individual patients. These meetings can be utilized by CES members (especially when they are taking part anyway due to their clinical tasks) to either explicitly discuss ethical aspects of a patient presented and/or to give short ethical inputs about presently discussed ethics literature cases, new court decisions, new laws affecting clinical decision-making etc. This also applies for established ad hoc meetings or patient case discussions in certain clinical situations where underlying ethical conflicts can be specified by CES members. The aim is to implement ethical argumentation in daily practice without introducing new organisational structures.

Concerning qualification:
One has to distinguish between qualifications for clinical ethicists themselves and healthcare staff as such. Meanwhile, there are various qualifications for clinical ethicists available (external and in-house qualification programmes, certification courses, master programmes). Also in small hospitals, it is more than desirable that some training (and certification) has to be obligatory for CES members (at least for chairmen/-women and vice-chairmen/-women) to possess basic knowledge of implementing CES and clinical ethics itself.

For clinical staff the aforementioned ethics rounds and in-house conferences each provide ethical briefings as a short but rather effective regular training. Further training of staff can be provided by special "ethics days" or within the established monthly further clinical education.

Concerning networking:
Especially for small (rural) hospitals it is necessary to get into contact with other CESs to exchange news, compare guidelines and report about conflict-solving strategies. Therefore, in some towns and regions, CESs of different hospitals can meet regularly once ot twice a year. Other healthcare workers are partly involved, such as physicians in private practice, or staff from nursing homes may participate. In the internet age, information flow and exchange can also be shared with others using internet platforms. These platforms additionally provide literature case discussions, information boards about special conferences, training programmes, literature and names of experts to contact.

Concluding, in small hospitals common problems of CES seem to be more obvious. But various ways exist to explicitly implement ethical aspects into daily routine by slightly modifying already existing organisational structures. Sustainability of work, qualification of staff and networking of CES are paramount. My

recommended longterm strategy is one of trial and error.

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CLINICAL ETHICS CONSULTATION IN ITALY: A NEW SCENARIO IS EXPECTED AFTER THE DOCUMENT OF TRENTO

a- The birth of the Italian Network and the Document of Trento
In Italy the debate about the role of clinical ethics and ethics consultation has brought about the need to create a National Group of Clinical Ethics and Healthcare Ethics Consultation. The National Group began to take shape and to be officially organized in 2010.
In June 2013 in Rome the National group started to draft a Document about Clinical Ethics Consultation in Healthcare in Italy. In October in Trento, at the Kessler Foundation, a committee with twelve signers approved the Document. The newborn document was called "The Document of Trento": it is the first Italian document regarding clinical ethics consultation.
The Document presents the definition of Healthcare Ethics Consultation – HCEC – as presented in a Report by the American Society for Bioethics and Humanities (*Core Competencies for Healthcare Ethics Consultation*, 2nd ed., 2011); the Ethics Consultation is "a set of services provided by an individual or a group in response to questions from patients, families, surrogates, healthcare professionals or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care". Clinical Ethics concerns the identification, analysis and resolution of bioethical issues current in ordinary clinical practice.
The Document of Trento is composed by five paragraphs: a) Ethical issues in clinical practice, 2) What is Ethics Consultation, 3) Who is the clinical ethics consultant, 3) Ethics Consultation Service, 5) The presence of Ethics Consultation in Healthcare Institutions. The Document took two strong stances: it considered Ethics Consultation as any other medical specialized consultation with some special features, and recognized the individual consultant as a more appropriate figure to conduct bedside consultations.
The Document resulted from a choral work of people with different cultural backgrounds who perform clinical ethics consultations in different ways; it was promptly endorsed by more than two hundred people. This Document is a first step towards improving the role of clinical ethics and ethics consultation as a central part of clinical practice to better treat the sick and dying. An ethical dilemma concerns all subjects involved in health care: what is the best thing to do in such situations? No one is alien to or exempted from the question: from the patient himself, to the health care providers as well as the family and the health care institutions.

b- An important step
The Document of Trento has generated an interesting debate about the practical need for Ethics Consultation Services and the role of the clinical ethicist in Italian hospitals: this last topic in particular has stimulated discussions between physicians and philosophers. Some forms of ethics services are already present in some regions, but in an informal and confidential mode. These unofficial consultations require selecting particular situations which are especially relevant to both the health care and the academic systems. However, the goal that the organizers of the meeting have proposed is to make a contribution to develop ethics services in Italy, especially in view of the fact that these services are already operating in the health care realities of many other European Countries.
For these reasons, on March 27th 2015 at Insubria University a meeting about the Clinical Ethics Consultation in the Italian Healthcare System was called. The National Group on Clinical Ethics and Healthcare Ethics Consultation promoted the conference. The considerations presented in the Document of Trento regarding the aims of Ethics Consultation ("improving the care of patients, with reference to both methods and results through the identification, analysis and resolution of ethical issues") were the core concept and the impetus for all of the reports.
The meeting was divided into two parts. During the first phase, various theorists, philosophers and bioethicists presented the theoretical and philosophical meaning of ethics consultation in health care systems. The second, more clinical phase was oriented towards reflections about the role of the ethics consultant in everyday clinical practice. The lecturers, specialists in different fields of medicine, made the focal point of their speeches, each one from their own specific vantage point, the issue and, indeed, the need to rely on Clinical Ethics Services in order to perform their daily medical tasks.
The debate focused on some important points: the role of the ethics consultant in a pluralistic social context; the ethics consultant's competences; the functions of the consultant, and the similarity between ethics consultation and all other types of medical consultation.
What kind of conduct is the ethics consultant called to adhere to in a pluralistic social context? The goal of the consultant seems to be to provide help regarding

making a decision which will often involve others. Choices must be, as much as possible, shared among the patient, the family and the health care team. The consultant acts for the good of those requesting a consultancy. The single clinical case is the starting point of the ethics consultation: the consultation is developed through both a specific setting and a particular relationship, it is inextricably linked to verbal and non-verbal communication skills, and it is directly applicable to daily clinical practice. The consultant's point of view must be "interlocutor oriented", e.g. helping him/her to further explore the rationale for his/her positions, but it must also highlight the critical issues regarding his/her conclusions. Ethics consultation can be request by the patient, and the patient's family in order to establish clear definitions regarding their present dilemmas and their choices for the future. A consultation can also be requested by physicians, nurses and health care staff as support regarding both what a most appropriate choice may be, and clarification of various available options. The administrative staff may also request the consultation, when it is necessary in order to better explain particulars regarding specific clinical cases or questions concerning health care policy.

Another issue concerns the ethics consultant's competences: he/she must have specific multidisciplinary training. The clinical ethics consultation needs specific skills to offer help to the applicant about a choice that generally has implications for the patient's life. In Italy there is no academic standard regarding the training of ethics consulting. This issue underscores the importance of defining the professional profile of the clinical ethics consultant.

The specificity of the consultant's educational process entails attending both academic courses (Masters and Ph.D.) in order to obtain theoretical knowledge (philosophical, medical, legal, theological), and internships in hospital wards in order to acquire specific practical skills and aptitudes. Vis a Vis this question, the Document of Trento explains that: "This position requires specific training. Although there is no *core curriculum*, there are Masters and PhDs, which will be specialized in Ethics Consultation. Training in bioethics is not sufficient: an adequate and specific education is needed to address issues "by the bedside of the patient, as well as at the decision-making level in healthcare. As an example, it is necessary to train professionals to be able to respond to emergency situations. The ethics consultant isn't an intermediary, a defense attorney, a spiritual consultant or a psychologist; he/she creates the conditions, he/she leads and helps subjects in taking an ethically sound and possibly shared decision".

Another important question is: should a single consultant or a small group provide the ethics consultation? The international experience shows that a single person, a small group, or the ethics committee of an institution can conduct an ethics consultation. Each of these models has their own potentialities and criticalities. In Italian settings, which are still marked by a lack of experience in institutionalized ethics consultation, the model of the single ethics consultant seems to be preferred for reasons of feasibility and sustainability. Certainly a single consultant seems to be more facilitated to organize the work and to move between different hospital wards where he/she might be called for a consultation. It is also appropriate that the Healthcare Ethics Consultation be integrated into an Ethics Consultation Service, constituted by a single consultant or a small team.

The ethics consultant should have the following functions: providing the consultations about clinical cases (the consultant with knowledge and training should be available to patients and medical staff to review a case, to offer informed and prudent counsel, and to assist in mediating conflict); supporting the drafting of guidelines of the institutional mission and the allocation criteria; ethical feed-backing about research protocols; systematic collection of ethical deontological documents (journals, books, encyclopedias, commentaries on judgments etc.); linking up with departments and ethicists operating on different levels (institutional, regional, national, international); connecting to the ethics committees (these two organizations need each other, they are not identical or interchangeable and their dialectic should be, in most cases, highly productive); planning, organizing and conducting continuous specific ethical training for clinical teams, individual health professionals, administrative organs and committees.

One last issue concerns the affinity between ethics consultation and all other types of medical consultations. The ethics consultant does not intervene as a mediator, as a defense attorney, as a spiritual consultant or as a psychologist; he/she creates the conditions, he/she leads and helps subjects in taking an ethically sound and possibly shared decision. The consultant has specific knowledge and skills, as reproduced in the Document of Trento, and can be called like any other specialist: "Ethics Consultation is a specialist consultancy comparable to all other health care consultations, but with some special emphases and peculiarities: a more closely and focused approach to relationships, dialogue, and pluralism, both in content and methods".

c- Perspectives and developments

The activities of the National Group of Clinical Ethics and Healthcare Ethics Consultation are largely directed to develop a professional profile of the clinical ethicist recognized throughout the nation. This profile will permit at various healthcare institutes to employ this kind of professional. For this reason in Italy since four years a second level professional Master in "Clinical

Bioethics Consultation" has been carried out to train the future ethics consultants. The master has been promoted and realized by different academic and nonacademic institutions: the Catholic University of Sacred Heart in Rome, the Insubria University in Varese, the "Federico II" University in Naples, the Lanza Foundation in Padua and the Local Health and Social Care Unit n. 7 (ULSS) in Veneto Region.

It is desirable that Ethics Consultation be implemented in Italy, in varying manners, respecting all local circumstances: the Health Institutions may integrate Ethics Consultation into its own organization or it can outsource Ethics Consultation as a service. It is strongly recommend that in Italy a clinical ethics service be introduced and nurtured as soon as possible.

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STARTING AN ETHICS SUPPORT NETWORK FOR JOINT CO-CONSTRUCTED ROFESSIONALIZATION OF CLINICAL ETHICS

This contribution deals with the realization of a nation-wide network on the professionalization of clinical ethics support in Dutch healthcare. Though clinical ethics support (CES) is provided in many Dutch healthcare institutions – and the number is increasing - its quality and impact are unknown. Research and experiences in many institutions showed that many ethics functionaries are working enthusiastically and persistently towards implementing various kinds of CES (particularly ethics committees, ethics consultants and moral case deliberation), but experiences or lessons are hardly shared. As a result, CES is strongly fragmented: quality-issues regarding CES remain unaddressed and every institution is re-inventing the proverbial wheel. As ethics deals with complex issues that may have a high impact, quality guidelines that support professionalization are important.

In reaction, the idea of creating a network on quality of ethics support was initiated. The Dutch Ministry of Healthcare (VWS) supported the initiative, financing the first two years to enable the start of the network. Three aims for this kick-off period were listed: 1. Realization of a network in which a diversity of participants from a theoretical ánd a practical background were included; 2. Organization of network meetings focussing on quality issues regarding CES; 3. Realization of concrete products regarding quality of CES such as a book or a website.

This contribution describes the *process* of sustaining a network that aims to include as many participants as possible who share their ideas and experiences regarding CES, resulting in national quality guidelines. It highlights processes of co-construction in terms of its successes, pitfalls and obstacles.

Starting a network

From the start, we aimed to include a diversity of participants in the network. We strived for maximum inclusion at the level of healthcare domains (care for disabled people, mental healthcare, elderly care, home care, (academic) hospitals), theoretical diversity (including multiple universities) and perspectives (ethics functionaries, teachers, academics, directors, managers, employees from the Ministry and from the healthcare inspectorate. This was important for three reasons: first, we wished for a broad input on existing practices, ideas and experiences regarding CES to realize rich and solid input on developing quality guidelines. Second, because we wanted a broad spectrum on quality issues regarding CES. And third, because the eventual sustainment of the guidelines should be widely supported to foster professiona-lization of CES in a broad sense.

A project group at the VU university medical centre was established to direct the project. Next, a sounding board was established with board members of healthcare institutions and ethicists from universities from all over the country. They were asked to critically follow the work of the project group in terms of its content, process, choices and ambitions.

Exploring ideas on CES quality guidelines

15 Representative ethics functionaries and academics were selected. They each were interviewed for about 1 – 1,5 hour. The interview topic list covered the following issues: goals of ethics support, the 'active substance' of ethics support, organizing and implementing ethics support, experience-based ideas on improving ethics support and visions regarding desirability, goals and functionality of the network. The interviewers strived for not only collecting ideas on

CES, but particularly to tie those ideas to the interviewees' practical experiences. The results of the interviews provided an important source of quality issues regarding CES.

A kick-off conference of 2 days was organized. For this conference, about 40 best informed people were invited as think-tank and hands-on participants on quality of CES. Again, the diversity of the meeting was deemed important. 27 participants attended the conference. The ideas regarding the network were presented as well as the first findings from the interviews regarding quality of CES. From the very start, the participants were invited to actively participate in realizing the network aims: formulating guidelines for Dutch CES in healthcare, based on their practical experiences and theoretical considerations. During the conference, dialogues were organized to intensify the search on quality guidelines.

The conference resulted in a dynamic and energetic meeting in which people were highly involved in the aims of the network and very willing to contribute in both the thinking and development process as well as the practical realization of the concrete network products. It meant a positive kick-off of the network that had no name yet. As the report of the conference was sent to the participants afterwards, they were asked to come up with a name: another way to explicate the participative character of the network, framing the shared ownership that was perceived important.

Enlarging the network

With the input from the 2-days conference, a larger conference of one day was organized. Participants from the first conference were asked: who from your CES-network should be invited to this conference? In this way the project group strived for broadening the scope of the network on the content level (experiential and theoretical input regarding quality guidelines for CES) and on a strategic level (including more people to enlarge the network). 40 Participants – with some overlap with the first conference – attended. First, the name of the network was revealed: NEON, a Dutch abbreviation standing for: Network Ethics Support the Netherlands. The name indeed came from input from the network participants.

In two sessions, participants were invited to further explore quality of CES, by answering the question: 'what does 'good ethics support' mean and imply?'. Outcomes of the interviews and interview codes were presented by the researcher of the project group. The participants were next asked to discuss the clusters that were based on the analysis of the interviews, by adding their experiences regarding each cluster and making the quality issues more concrete.

Obstacles and lessons learnt

The structure of this conference however appeared tricky in the process of stimulating CES-workers to participate in the network. The presentation of the interview outcomes was perceived as academic work detached from (their) practice. Shared ownership seemed far away: some participants felt they were respondents in a research project rather than participants in a network. Also, participants expressed that they feared the development of quality guidelines would result in a static prescriptive tick-box or checklist rather than an overview of guiding principles. The plenary discussion on that latter issue revealed however some important insights regarding the development of quality guidelines for CES: some participants were against this development, because of the risk of a tick-box result. Others said it was perceived important and useful to share and explore what exactly CES consists of and how quality can be obtained.

Throughout this process, we learnt that a process of shared ownership and a democratic structure in developing quality guidelines is not a given. The issue of credibility on the inclusion of participants and the co-creative structure deserved continuous attention. Also, we learnt that the collective thinking process on quality of CES was welcomed and deemed important. Participants were highly engaged during the meetings and in between conferences they spontaneously send in their comments, reactions, worries or ideas. This showed the importance of the joint search for quality and the urgency of being included in the process. At the same time, participants worried about the future status of the quality guidelines on CES resulting in a one-dimensional tick-box list rather than a rich description of quality guidelines. In other words: they welcomed the idea of a thinking process and were eager to attend the organized conferences to have their input, but the step towards formulating concrete quality guidelines did not immediately appeal to everyone attending.

Applying the lessons for the future development of the project

As a result, the project group decided to strengthen the co-creative character of NEON, without losing the focus to the future developments. The aim was to insistently include practice experiences as learning material on quality of CES and at the same time to work towards concrete results.

During the third conference, the recently developed website was presented. This conference had the same structure as the first invitational conference: best informed ethics functionaries were invited for a 2-days

conference. The meeting again was highly dynamic. The program focussed on the creation of the products that were being aspired, in particular the website and the CES handbook.

The presentation of the concept of the website at the beginning of the conference set the tone. Representing contributions of participants that attended (rather than contributions of the project group or academic findings) immediately showed that the input from participants was fundamental in the search for quality on CES. Participants were very enthusiastic and proud of this result – as, by the way, was the project group. It provided a concrete example of the products NEON strived for.

The next day, participants worked towards the handbook on quality of Dutch CES. After exploring the ideas regarding CES through a plenary, structured format, the group was divided into six sub-groups. Each group constructed an outline one chapter of the handbook-to-be regarding one particular issue on quality of CES: what should be in the book according to you? After several hours of solid work in subgroups, followed by a plenary discussion, the table of content of the book was ready. Made by the participants.

Next, a larger conference again was organized in which the participants were invited to share their best practices in subgroups to allow other participants to draw lessons for their own practices. Again a dynamic conference was realized in which the participative and co-creative character of NEON stood out. During this conference, the website was officially launched. In the pre-phase of this conference, all former participants were approached to send in their digital profile and their best practices to be published on the website. Also, they were asked to approach other people from their networks to send in their contribution. Within weeks, the website showed a broad spectrum of ethics practices and research coming from any healthcare domain possible.

Future steps

NEON started in January 2014. In 1½ years, four conferences, a website, 115 active participants and the start of a handbook were achieved. At this point, a handbook is being written by members of the project group, following the structure that was co-created at the third NEON-conference. Participants are invited to comment on the chapter(s) of the handbook of his/her choice. 30 Participants replied positively and eagerly to that invitation: this way, the book will also origin from the network.

In Spring 2016, the project-phase of NEON will be completed by launching the handbook on quality of CES during a final conference. The book will reflect the atmosphere during the previous conferences with lessons learnt (that are translated in quality guidelines) and exemplary best practices from participants. After that, the project group aspires to continue the work on quality guidelines of CES by research on how they work in practice. This research will provide answers to the concrete applicability of the NEON quality guidelines as well as how (and if) they can best be implemented.

This contribution described the process of creating a network aimed at establishing quality guidelines of CES in Dutch healthcare. Rather than the content, we described the process of how co-creation of such an aim reveals the great potential of experiential lessons from people coming from practices they are highly engaged in. It shows the process of precariousness on how to relate to network participants who are working towards concrete products and the tensions that may bring. And, reversibly, how uplifting and stimulating this co-creative process can be once participants feel sincerely included in the development process. The final aim is to work towards a less defragmented, and a more professionally institutionalized CES-service within healthcare institutions by bringing lessons from theory and practice together. The first steps taken have been intense, yet very encouraging.

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GETTING ETHICS SUPPORT INTO HARD TO REACH PLACES. A UK PERSPECTIVE

Whilst ethics support services have become well-established across the UK in recent years – mainly in the form of ethics committees – those people who provide care beyond the clinic lack comparable forms of guidance in difficult ethical decision-making. A similar pattern has been observed in other countries, (e.g. Libow *et al.,* 1992; Dauwerse *et al.,* 2012) and pertinent questions remain about how ethics support can be best extended to non-clinical, and non-hospital based care environments.

At least part of the blame for this blind-spot in today's landscape of ethics support activities must be placed upon those working in an academic field that still largely refers to itself as 'medical', 'clinical', or 'health

care' ethics. The evolution of clinical ethics support services in the UK has largely tracked the academic study of the 'big issues' in medical ethics: decisions, around withdrawing or withholding life-sustaining treatment, organ transplantation, and consent to treatment, for example. Whilst there is increasing recognition of the everyday ethical issues that arise in paid and unpaid long-term and community care settings (Baldwin *et al.,* 2005; Hughes and Baldwin, 2006; Kane and Caplan, 1990; Powers, 2003; van der Dam *et al.*, 2011), this growing level of interest has not yet bled down into the systematic analysis of questions relating to ethics education, training, and support. By and large, it is within hospital settings that the decisions to be made in relation to such issues become visible (even if these issues are not limited to these locations), and therefore it is in these settings that the need for assistance in making difficult ethical decisions has been identified. Tellingly, it is also often the very same hospitals that have close academic connections with those working in medical ethics departments, and so the path from the ethics centre to the hospital ward or boardroom is a relatively easy one to tread.

Overarching models for the provision of care might also go some way to explaining this limited extension of ethics support activities. In the UK, at least, the institutional divide between health services and social care services remains marked. The National Health Service (NHS) has primary responsibility for the provision of publicly-funded health services, including mental health services, but it is local governments (councils) across the country that co-ordinate and manage the delivery of social welfare services, pre-dominantly making use of private care organisations within a means-tested framework. Whilst there have been attempts to integrate so-called health and social care within so-called 'partnership services', this longstanding divide may also partly explain why community-based social welfare services for children, older adults, people with disabilities, as well as other institutional settings such as nursing homes, residential care homes, and home- and respite-care services remain largely cut off from ethics support activities. In this article, I will use the term 'social care services' to refer to this large range of different care and support activities.

Filling this lacuna is important, but not entirely straightforward. In my own attempts to instigate ethics support activities within community-based and long-term care settings, I have become increasingly persuaded that the solution is not simply to advocate that medical ethicists 'open their eyes' to spaces of care beyond the clinic, or that they need to be sensitive to the main institutional differences between health and social care delivery. In what follows, I draw on my personal experiences in order to provide a brief outline of a range of cultural and practical challenges that I believe need to be overcome in order to develop ethics support in these different settings. I conclude by discussing how such challenges might be overcome in order to provide appropriate forms of ethics support.

Identifying barriers

Community-based care services differ from acute services in a number of ways. It is fair to say that a nursing home does not feel very much like a hospital, and such differences between the cultures of particular institutions are not best captured by reference only to the different services provided within each. In contrast to the health care setting, it is not common for outsiders to the social care environment to enter social care services in order to provide guidance or advice, particularly when those individuals carry university affiliations on their business cards. This scepticism might be explained, at least in part, by the less well established academic research culture in social care, the close-knit nature of many professionals working in a single institutional setting, and the fear and doubt that is fostered amongst professionals when there is limited public awareness about their roles beyond the occasional media reports highlighting scandals in care quality.

Such scepticism towards the outsider entering the care home or the community care centre is heightened further when the focus of the activity is in identifying and discussing ethical problems in practice. Encouraging discussions to focus down on the good and bad of decision-making is only likely to heighten staff members' concerns that their performance is being subject to external (negative) judgement, and that they are being exposed to a degree of scrutiny that differs markedly from their usual experiences at work. The word 'ethics' itself is likely to give rise to confusion and uncertainty. Such discussions about ethics could also further foster concerns that the ethicist is looking to unearth problems that could have implications for their employment status in the setting, or its reputation more generally, particularly when these settings are characterised by hierarchical structures in which an openness to discussion or sharing information between staff members in different roles is limited.

Given this, it is perhaps unsurprising that care managers have often responded to initial contact about developing ethics support with the claim that their setting has established a number of policies to deal with the kinds of issues that would be widely recognised as worthy of broader ethical discussion. Whilst the challenge in navigating between legal and ethical content in support services of this kind is

commonly recognised, it is apparent that care workers' support activities are closely managed through a range of local procedural requirements that determine how they ought to behave in any given situation. This is not to suggest that an upshot of this policy-driven approach to care work means that care workers face no ethical issues, but rather that it is a widely-held (though in my experience false) assumption that such staff members receive all the assistance they require in addressing ethical problems in their work.

More structural barriers also exist in developing a sustainable form of ethics support in social care settings. Social care settings are often built around shift working, making it difficult to schedule ethics support activities that a large number of people can participate in. There is also a large proportion of agency staff in employment in this sector, and high staff turnover rates, which undermines the continuity of individual participation in ethics support activities that is so crucial to its success. Staff from different cultural backgrounds are also very likely to be working alongside each other in social care (as is also the case in health care), but the lower skill-base associated with the majority of the social care professions means that it is possible that these individuals will have a poorer grasp of the English language, and therefore find it more difficult to participate in ethical discussions.

Overcoming the barriers

As mentioned above, the standard approach to providing clinical ethics support in the UK is through a clinical ethics committee. There are a number of reasons to think that this tried-and-tested model is inappropriate for the social care context. A committee that meets regularly to address ethical issues arising in a particular institutional setting is likely to reinforce the hierarchical working structures in a setting such as a care home. One implication of the introduction of a committee-based approach is that it is uncertain whether those employed as front-line care workers would feel confident to refer any cases. Another implication is that it is unlikely that a committee of this kind would be able to instigate an approach to ethical reasoning that could move beyond a conservative approach to reinforcing the standard policy- and procedure-led approaches to care provision and decision-making. Moreover, given the limited training and support offered to front-line staff otherwise, it is also unlikely that an ethics committee could offer sufficient support to those who are being required to make judgements about the various 'mundane' ethical challenges that they continually encounter (Dauwerse *et al.*, 2012).

As I have discussed elsewhere, I believe that the ideal approach is to foster the development of "a model of

ethics support that can be implemented straightforwardly in the different settings in which care is provided, and that can incorporate skill development and training components within a self-reflective and formative approach to addressing ethical issues." (Hope and Dunn, 2014).

Straightforward implementation of an approach of this kind is important because social care services are financially stretched, and it is helpful to be able to convey – quickly and cheaply – to care provider organisations that ethics support can offer clear and cost-limited benefits to their services. Connecting ethics support with direct training initiatives looks to be of particular value given the lack of educational opportunities in ethics for social care workers during their professional development.

A self-reflective and formative approach to ethics support provision is also likely to be appropriate for a number of reasons. First, in a culture of care work in which staff behaviour is modified by a vast range of policies and procedures, it is important that these individuals are able to maintain ownership of the difficulties they face in their day-to-day work, even if these difficulties might arise about judgements about the appropriateness of following a particular policy in any given situation. Convening a group of people to share the difficult decisions in their own terms, to identify common issues, and then to subject these issues to critical ethical analysis by reference to the values and concepts that the care staff themselves invoke would help to ensure that the discussion of the ethical challenges identified would never venture too far from their own experiences and the vocabulary that they are comfortable with.

The development of networks of community practitioners in ethics (www.communityethicsnetwork.ca) and deliberative meetings or ethics rounds around real cases (Libow *et al.*, 1992; Abma et al., 2009; van der Dam et al., 2011), seem to be better placed to ensure that ethics support mechanisms are responsive to the issues raised by those working in these settings. This 'ground up' process can also help to ensure that reasoning through ethical issues is sensitive to the governmental and institutional policies and procedures that must be adhered to in care settings, the requirements of local and national legal frameworks, and the perspectives and individual values of all those involved in the practice of care. Moreover, these more informal processes are more likely to be integrated seamlessly into the daily patterns of professional life in the care setting, helping to ensure that ethics support of this form is welcomed as an adjunct to, rather than a distraction from, the working regimes of community- and residential-based care settings.

So what specific approaches to social care ethics support ought to be adopted within these different models? There is unlikely to be a single right answer to this question. Rather, the appropriateness of any given approach will depend on the institutional set up in question. Ethics support in a geographically diffuse and multi-disciplinary community service for people with enduring mental illnesses in central London will need to be designed very differently from a support service established in a single care home for people with dementia living in a rural village. Moreover, the success of ethics support activities will depend in part on their flexibility; being able to adapt ethics support to the particular socio-cultural dynamics of each institutional care setting, to what works and what doesn't work 'on the ground', and to what best enables the individuals in question to adopt a self-reflective but critical stance on the difficult decisions they face, is crucial.

Notwithstanding this point, a few general observations about the *form* of appropriate ethics can be made. Within whatever model is adopted, the role of the facilitator of an ethics support meeting will be different from that of the clinical ethics committee member or the ethics consultant. Her primary role will be to ensure that practical ethical issues experienced by those working in care are raised for discussion, that the relevant ethical considerations are introduced in a suitable manner, and that participation in discussions is encouraged. As ethical issues are identified and scrutinised, this role will also involve adopting a set of ethical 'tools' that encourage care staff to reason carefully through practical problems. These tools might include the use of case comparisons and thought experiments, the ability to distinguish facts from values, and the balancing of principles and intuitions. Given the limited exposure of social care professionals to ethical education in their training programmes, the acquisition of such skills is likely to go some way to equip the care staff with techniques that can enable them to reason through ethical issues as they encounter them during their work.

Given that the majority of the ethical issues that have been documented in professional social care settings also apply to family care environments, another process that needs to be given serious consideration is the provision of training and support in ethics in family care settings. In those home environments where family carers receive input from social services or community care practitioners, ethics input should be an additional component of the support provided. When family carers do not receive such additional support, information about ethical issues could form part of information made available within primary care, and proactive efforts might be made by dementia charities and other non-governmental organisations to infuse an ethics component into the information that they provide about dementia – as has recently happened with work completed by Alzheimer Europe (2014).

In conclusion, there remains a pressing need to develop ethics support in social care settings. Those working in these care environments face a range of different, but equally difficult, decisions to those working in health care. Instigating ethics support in social care is not simply a matter of translating well-established models from clinical ethics activities. Rather, models of ethics support need to be carefully tailored to the unique institutional and socio-cultural make up of different kinds of social care provision. Within these models, ethics support needs to take a different form and, whichever model is adopted, the challenge will be to ensure that deliberative spaces of ethical reflection and inquiry connect participants' own experiences, attitudes and insights with the critical, analytic techniques that can enable justifiable answers to be articulated for the various ethical questions posed.

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