'Measuring' Ethics Support in the Clinic:

Current Challenges

21th April 2016, Bern, Switzerland

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SAMS: Ethics support in medicine (2012)

" *… ethics support structures are only useful if they fulfil their functions in an appropriate manner.*" (p. 5)

"*Ethics support is designed to facilitate decision-making for individuals and institutions…*

It should also enhance the transparency of decision-making processes, promote the recognition of conflicting values or interests and indicate ways of resolving such conflicts.

… offer systematic support for care teams and management in dealing with ethical problems and conflicts.

Ethics structures should thus make a significant contribution to the quality of treatment and other services." (p.7)

MANY GOALS OF ETHICS SUPPORT … ARE THEY FULFILLED?

SAMS: Ethics support in medicine (2012)

"It is important that ethics structures should have the resources required to evaluate the quality of their activities. However, it should be stressed that evaluation of the quality of ethics support is a delicate matter – one cannot simply apply the quantitative tools used in other areas.

The SAMS would welcome research relating to the quality of clinical ethics support structures." (p.24)

CAN RESEARCH BE USED AS A CYCLIC PROCESS TO *DEVELOP* QUALITY CRITERIA?

"*To evaluate the quality of ethics support, it would be important to define objectives and assess the extent to which these are attained. This would require* **extensive reflection on the appropriateness and validity of the evaluation criteria** *selected.*

Sharing of experience and expertise within a network of ethics structures should therefore be promoted; this could include, for example, a peer-to-peer review system. Feedback can also be requested from users." (p. 24)

WHO DEFINES THE OBJECTIVES OF CES?
WHAT ARE APPROPRIATE AND VALID EVALUATION CRITERIA?

SHARING EXPERIENCES: DUTCH EXAMPLE 'NEON' (2014-2018)

Outline of presentation

- CES and central goals

- Why measure? Why not measure?

- What to measure? How to measure?

- Examples of current CES evaluation research

- Conclusion & discussion

Clinical ethics support (CES)

Various types of explicit CES

- (Health) Ethics committees

- Ethics consultants

- Moral case deliberation / ethics reflection groups

- Ethics rounds

Also:

- alternative types of CES (e.g. training)

- implicit ways of CES (e.g. coffee corner, team meeting)

Various types of CES are aiming at different goals

Goals of Clinical ethics support*

- Case: insight, lessons, consensus/compromise, solution

- Professional: moral competency, self-care (moral distress), motivation

- Team: decision-making, dialogue, cooperation

- Institution: culture, policy, codes of conduct, mission/identity

Goals of CES depend on context/users

* Molewijk et al (2008). Implementing moral case deliberation in a psychiatric hospital: process and outcome. In: *Med Health Care and Philosophy*, 11, 43-56.

Why CES evaluation research?

- CES is a relatively young field with no clear standards for quality & some concerns about low quality of CES

- CES is a way of offering support: in which way are CES requesters supported?

- CES is not a goal in itself: does CES reaches its goals?

- Cyclic process of professional & quality development

- Support & facilitate implementation of CES

- Co-create and stimulate co-ownership of CES

Research is a cyclic process of reflecting on and co-constructing the quality of CES

Why NOT CES evaluation research?

- It is time consuming and expensive

- It can disappear in universities and journals …

- It can become another bureaucratic process away from the core business of health care institutions

- It can be used against CES (weak, negative or lack of findings)

- CES outcomes can become the aims of CES

Kinds of CES evaluation research*

- Registration of use of CES

  – E.g. frequency, themes, requesters, etc.

- Evaluation of CES itself

  – E.g. process, group, facilitator, outcome, etc.

- Evaluation of content of CES

- Outcomes of CES, such as:

  – Improved quality of care

  – Improved decision making

  – Improved team cooperation

  – Improved moral competency of professionals

*Schildmann et al (2013). Evaluation of clinical ethics support services. Journal of Medical Ethics, 39(11), 681-5.

Attention for evaluation of CES outcomes

Outcomes of CES

Not focusing on the CES activities itself, but the experienced or observed outcomes (in)directly related to the CES activities

- Experienced outcomes
  - e.g. Oslo PET study: change in experienced team cooperation, dealing with disagreement & attitudes towards coercion
- Observed outcomes
  - e.g. amount of days on IC unit (Schneidermann et al, 2003)

Focus on impact on quality of care & life

Within CES outcomes research, more focus on CES's impact on, or contribution to, quality of care & quality of life is needed

- Quality of care (various domains of quality)
- Quantity of care (what and how much is used)
- Quality of patient's life

Double loop: (clinical) ethics is about reflecting upon and defining quality (of care); CES research should do the same

In the end, direct or indirect impact on quality of care and life is one of the core justifications for CES

What kind of research and how to use it?

- Research is often seen as an separate activity from practice (independent, neutral, distanced)

- Traditional research: first determine criteria & outcomes, then start to measure

However, for practical and theoretical reasons, a more **responsive evaluation design** for CES, in which all stakeholders become research partners, is important (Guba & Lincoln's 'Fourth Generation Evaluation', 1989).

Fits with dialogical processes (in ethics) as vehicle for learning, understanding & (re)construction of norms for (ethics) quality

Special role of CES evaluation research*

- Evaluation research can facilitate and adjust the implementation of CES within a health care institution

- Evaluation research can stimulate co-ownership and responsibility of the CES requesters: 'What do YOU want with CES?' (note: preferences are not = quality of CES)

- Evaluation of content of CES can result in development of policy, ethics guidelines, moral compass, etc. (e.g. MCD as research)

* Abma et al (2009). Good care in ongoing dialogue. Health Care Analysis.

Two examples of CES evaluation research

1. European development of questionnaire for measuring outcomes of moral case deliberation (EURO-MCD)

2. Developing Dutch quality criteria for ethics support through responsive evaluation and 'communities of practice' (NEON; 2014-2018)

Example 1: Measuring MCD outcomes*

Questionnaire on MCD outcomes by European expert panel: the EURO-MCD questionnaire: 6 domains, 26 MCD outcomes

- **MCD improved moral reflexivity**
  - e.g. '*MCD develops my skills to analyse ethical difficult situations*'
- **MCD improved moral attitude**
  - e.g. '*Gives me more courage to express my ethical standpoint*'
- **Enhanced teambuilding**
  - e.g. '*I & my co-workers manage disagreements more constructively*'
- **MCD enhanced emotional support**
  - e.g. '*Enables me to better manage the stress*'
- **Improvement on organizational level**
  - e.g. '*Contributes to development of practice/policies in workplace*'
- **MCD contributes to concrete results**
  - e.g. '*Through MCD we find more courses of actions*'

* Svantesson et al (2014). Outcomes of Moral Case Deliberation. BMC Medical Ethics

EURO-MCD: measuring MCD outcomes

Use of EURO-MCD questionnaire:

- T0 (before MCD)
- T1 (after 4 MCDs)
- T2 (after 8 MCDs)

Central research questions:
- How important are these MCD outcomes for you?
- Did you experience this MCD outcome within MCD?
- Did you experience this MCD outcome in your work?

Open questions:
- Which outcomes do you prefer and value?
- How would you prioritise these outcomes?

Now: psychometric validation in 5 European countries (PhD)

Euro MCD: some Dutch results*

331 Dutch care professionals, *before* participating in MCD (T0)

- Most important domain: **Enhanced collaboration**
  - *'more open communication', 'better mutual understanding', 'feeling safe', 'mutual respect' & 'better listening'*
- Furthermore: **Improved moral reflexivity**
  - *'see the situation from different perspectives', 'identify the core ethical question' & 'develop skills to analyse'*

Next step in research: European comparison of MCD outcomes

* Trimp et al (2016). What outcomes do Dutch healthcare professionals perceive as important? *Submitted*

Euro MCD: predefined outcomes?

YES

- 26 outcomes are literature & experts based

NO

- Outcomes from literature are partly from CES users

- EURO-MCD asks openly: what outcomes they prefer

- Additional interviews (qualitative data)

- EURO-MCD can be used in order pay attention for differences in outcomes and give CES users a voice

Example 2: Dutch quality criteria for CES

Network Ethics Support the Netherlands

A national network for sharing and exchanging experiences (good practices) in order to professionalize and improve CES

Background:
1. CES field is fragmented, institutions and professionals run the risk of "reinventing the wheel";
2. Unclear and no consensus on what quality of CES entails;
3. Quality of CES is highly dependent of the individual

(see suggestion from SAMS Ethics support in medicine, 2012)

NEON: Research Design

- Developing quality guidelines through a learning network, based on practice experiences of professionals within CES

- Learning network: a community of practice, appreciative inquiry

  - *Research method is a change instrument*

  - *Starts from experiences*

  - *Co-creation of knowledge/expertise*

  - *Assures support for the quality guidelines*

  - *Creates a shared foundation for quality guidelines*

  - *Emerging design*

NEON: method & data (2014-2018)

- 25 semi-structured interviews (transcribed/analyzed)

- Expert meetings & national conferences (reports and discussing results from interviews)

- Collect and analyze best practices from NEON members (now put on the NEON website)

- Write best practices down & extract quality criteria

- Comments from NEON members on text (national manual book on best practices & quality criteria)

- Now: training audit teams and arranging mutual audit teams followed by research

Conclusion CES evaluation

- Plea for more attention for CES outcome research, in particular focusing on CES's impact on quality of care & life

- CES evaluation research is a way of facilitating implemention and co-ownership of CES in various contexts

- CES evaluation research can be more dialogical: i.e. joint ownership regarding the quality of CES through cyclic learning processes

CES evaluation research is needed and should be integrated within CES activities!

Thank you for you attention!

PS In 2016: a thematic issue of evaluation of CES in **Bioethics** (editors: Slowther, Schildmann, Molewijk)

PS On 7th of September 2016: present & share your research at the **ECEN Open Forum Day** (from European Clinical Ethics Network) in Leuven (Belgium)

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