Innovations in Clinical Ethics Support

Hartman, L.A.

2020

document version
Publisher's PDF, also known as Version of record

SUMMARY

The growing need to support health care workers on ethical issues has led to the development and implementation of Clinical Ethics Support (CES) in countries the world over. Although CES is viewed favorably, it also faces some serious challenges. This dissertation presents three CES innovations aimed at addressing these challenges. Firstly, we designed a CES tool aimed at increasing the impact of any insights acquired through MCD by spreading these insights across the organization. Secondly, we developed an integrative approach to CES—a new way of providing and organizing CES—in order to increase CES's impact and encourage more requests for support. Thirdly, we conceptualized and fostered the quality of CES with the aim of promoting consensus about what constitutes good Clinical Ethics Support. By experimenting in practice with these innovations, reflecting on our experiences and bringing theories to bear on them, we described several key characteristics of these innovations, making them informative for other local CES practices. We found that these innovations indeed addressed part of the challenges we identified.

The empirical findings and theoretical reflections in this dissertation functioned iteratively. We did not arrive at our findings by applying theory to the empirical findings or vice versa. Instead, we iteratively deepened our understanding of our empirical findings by reflecting on them theoretically, and through this process also made general theories more concrete, articulating the theories' implications for the CES innovation at hand. One example of this was the formulation of the key characteristics of a CES tool. Each section of this dissertation presents a CES innovation. Each innovation is described in two chapters, one of which describes the empirical process while the other provides the relevant theoretical reflections underpinning the research.

Chapters 2 and 3 (Part A) describe the development of a CES tool known as the 'moral compass', based on Moral Case Deliberations. We developed this CES tool at the request of a health care facility that asked us to disseminate the insights acquired in MCDs throughout the organization. This study's research objective was to develop an innovative CES tool based on a series of MCDs, aimed at increasing the impact of MCDs on the health care organization and at fostering moral learning across the organization. The CES tool had a specific theme: moral challenges regarding client autonomy. Our aim was to create a more accessible and time-efficient way of offering CES and to integrate insights and

suggestions from earlier MCDs in a new CES tool. Chapter 2 describes the CES tool and Chapter 3 presents our theoretical reflections on the tool.

The CES tool we developed was meant to help users who are facing a moral question. The tool consists of a booklet that poses six follow-up questions, all of which are meant to aid the user in dealing with the original moral question. Accompanying each follow-up question is a sentence explaining how answering that question can help the user in grappling with the moral question (the intention being to aid the user in understanding the specific question) and how the answer to that question may be helpful to the user. The six questions are illustrated with examples based on the analysis of the MCDs. These include issues that earlier MCD participants struggled with, and best practices for dealing with the moral question identified by the MCD participants.

MCDs are case-based. MCD emphasizes the importance of context when contemplating the right thing to do. Thinking about the right thing to do implies a specific 'here', a place and time, with contextual details and stakeholders that are relevant at a given moment. How can these insights be transferred to a CES tool? In order to address this question, we identified four core characteristics of a theme based CES tool based on MCDs (see Chapter 3): (a) an actual experienced moral problem as starting point of the CES tool; (b) focus with the CES tool on moral inquiry into the moral concepts, questions and routines within the lived experience of the CES tool user; (c) stimulate moral learning by exploring other perspectives; and (d) incorporate contextual details (both content-oriented and procedural) that can be relevant for the user of the CES tool.

Chapter 4 and 5 (Part B) of this dissertation describe the development of an integrative approach to CES. As described in the Introduction to this dissertation, traditional CES often receives too few support requests and has limited impact on clinical care. We experienced the same with regard to MCD. Furthermore, in the case study—which involved offering CES to a team that provides care for transgender persons, we initially found that the team did not have a real sense of ownership with regard to MCD. MCD was mainly considered the MCD facilitator's responsibility. Following up after MCDs and addressing the more systemic causes of moral dilemmas proved challenging. To meet these challenges, we started experimenting with innovative CES activities and organizing CES in a different way. Based on a cyclical process alternating between theoretical reflection and practical experience, we drew sixteen lessons (Chapter 4) and formulated five key characteristics for an integrative approach to CES (Chapter 5).

Chapter 4 describes in detail the CES activities we developed for the Centre of Expertise on Gender Dysphoria (CEGD). We began by providing MCD during CEGD policy days. Following an evaluation study of the MCDs and steering meetings, this gradually evolved into other CES activities, such as the CES staff joining multidisciplinary meetings, an observational study into the themes underlying the moral issues experienced, and co-creation of an ethics logbook. In addition, we collaboratively developed and performed CES on training days and at educational and international conferences. The sixteen lessons we draw are directly related to our experiences and the challenges we faced in the course of these new CES activities.

Chapter 5 describes five elements we identified as key to an integrative CES approach. Inspired by the theories of hermeneutics and pragmatism we reflected on our experiences in the integrative CES case study and identified these five key characteristics. We had no predefined idea of what integrative CES would or should look like. Instead, we derived these key characteristics of integrative CES by first developing CES activities in practice and then reflecting on our experiences, relating them to theories on hermeneutic ethics and pragmatism, and finally giving them a name. The five key characteristics are 1. Positioning CES more within care practices, 2. Involving new perspectives, 3. Creating co-ownership of CES, 4. Paying attention to follow up, and 5. Developing innovative CES activities through an emerging design.

The third innovation presented in this dissertation pertains to the way we conceptualized and fostered the quality of CES. Although there is increasing awareness of CES in regulatory agencies such as JCI, there are still many questions about what constitutes the quality CES. This regards both more conceptual questions—about what qualitatively good CES actually looks like—and more empirical questions, such as: 'What level of quality does CES in health care organizations currently have?' and 'How do you foster the quality of CES?' Chapters 6 and 7 (Part C) of this dissertation describe the process and outcome of conceptualizing CES quality and fostering good CES in the Netherlands, through the development of a Dutch National Network called NEON.

Chapter 6 describes one particular outcome of this process; a set of 60 quality characteristics for CES in the Netherlands. The quality characteristics presented there deal with four domains: 1. Goals of CES, 2. Methods of CES, 3. Competences of CES practitioners and 4. Implementation of CES. The variety and scope regarding CES and health care sectors stand out compared to similar ef-

forts by CES networks in other countries. The characteristics describe the general requirements for qualitatively good CES. For instance that a conversation method is advisable for a CES activity like an MCD , but do not specify which specific CES method. Relatively few quality characteristics actually address the quality of a CES *activity itself* or its outcomes, in other words answering questions such as: 'What constitutes a qualitatively goof ethics committee meeting?' or ' a moral case deliberation?'

Chapter 7 describes in greater detail three activities we organized to conceptualize and foster the quality of CES in the Netherlands: 1. Organizing expert meetings and national conferences to facilitate a dialogue on CES quality, 2. Launch of a website and publishing a national handbook on CES, and 3. Organizing responsive quality assessments about the quality of CES. Additionally, this chapter reflects on the methodology we used and describes five similarities between a responsive evaluation methodology and our theoretical understanding of CES. Firstly, they share an emphasis on dialogue between stakeholders. Secondly, they underscore the importance of experiential knowledge and contextual details in the process of conceptualizing and fostering what is morally good or a good practice. Thirdly, both try to avoid producing abstract or general principles that have to fit all cases and prescribe from an external perspective what should be done. Instead, both attempt to assist stakeholders in reaching a fuller understanding of their practice or situation by including more perspectives and encouraging reflection on their (perhaps implicit) way of looking at a practice or case. This can be encouraged by the use of a general principle, which in that case functions merely as a heuristic tool. Fourthly, both view diversity or pluralism of ideas not as problematic but as an opportunity to learn and improve. Fifthly, both approaches entail engagement with the practice under consideration rather than an outsider perspective that 'objectively judges' a practice, and a commitment to the viewpoint that all voices should be heard and taken seriously.

This dissertation presents three innovations covering a broad spectrum of CES, as well as our theoretical reflections combined with empirical research. Theoretical presuppositions are frequently left implicit in research on CES evaluation and innovation. Reflecting upon these presuppositions allows scholars to steer the research process more transparently and less implicitly. The same principle is relevant to the evaluation of CES outcomes. To evaluate CES, it should be made explicit on what grounds the evaluation is performed. The theoretical

reflections in this dissertation make it possible to steer the rationale and the course of the desired innovations and evaluate the innovations accordingly.

In the discussion (Chapter 8), we first briefly summarize the specific innovations and subsequently reflect on the strengths and weaknesses of each study. Next, we reflect on our pragmatic hermeneutic approach to CES innovation research. We consider the use of pragmatic hermeneutic theory as well as the normativity of the research. Then, we address the concern that pragmatic hermeneutic research could tend toward moral relativism and that the participants in an MCD or a similar kind of CES could come to a decision which is 'morally wrong'. Subsequently, we discuss whether it is consistent for CES with a pragmatic hermeneutic background to develop or implement rules or protocols. Finally, we discuss whether, and to what extent, the CES challenges described in this dissertation are adequately addressed by the innovations presented.

This dissertation is part of the effort to professionalize CES and make it more effective and theoretically grounded, thereby enhancing its impact and quality. Among our findings, we conclude that CES should be less far removed from clinical practice than it is at present. It is important to organize it closer to the practice of care, while ensuring that there is enough space outside clinical practice for participants to reflect on their experiences. Overall, we believe that normative evaluation in CES is best achieved in dialogue with as many stakeholders as possible. CES should focus on a careful critical examination of what is actually going on in clinical practices. Collective judgements about whether these situations are fostering good care in the best way we can currently conceive are all we have. We hope the research presented in this dissertation will inform and inspire other CES practitioners and researchers to study and experiment with innovations in CES in their own local CES practices.