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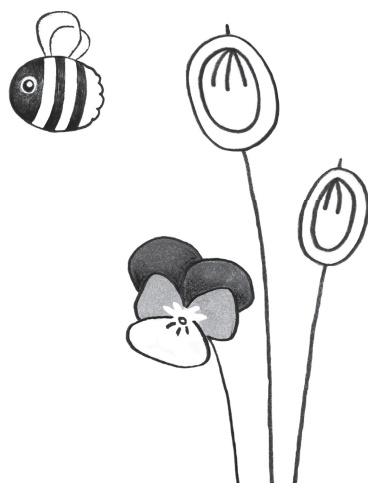
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Summary Samenvatting



SUMMARY

The central aim of this thesis is to use, test and improve the European Moral Case Deliberation Outcomes (Euro-MCD) Instrument from 2014. This Instrument measures outcomes of moral case deliberation (MCD), a form of Clinical ethics support (CES). In an MCD meeting, healthcare professionals engage in a group dialogue about a moral question encountered in an ethically difficult situation. The meeting is guided by a facilitator who might use a conversation method. In the Introduction (**Chapter 1**), the aim of the thesis is introduced against the background of CES in general and MCD. The Introduction further describes the need for more systematic and evidence-based tools for evaluation research in this field of ethical support.

CES services intend to support healthcare professionals in managing ethically difficult situations. They have become recommended services in various healthcare settings in Europe. There is a need to know whether CES services actually support healthcare professionals in this. More specifically, it is important to know what the outcomes of CES are. This information can be used to improve implementation, quality and facilitation of the CES service. However, evaluation of CES outcomes is complex, because CES itself is complex and performed in various ways. General definitions of 'good' CES outcomes do not fit since these definitions depend on the contexts and aims of the specific CES service. What a 'good' outcome would be is also exactly the question in the CES service itself (like during an MCD session): what is good care in this situation? What is the morally right decision here? In addition, regarding the hermeneutical philosophical background of MCD, moral expertise is supposed to be within the group of MCD participants, *they* deliberate about these normative questions. According to this theoretical perspective on clinical ethics and CES, the voice of MCD participants (or CES end-users), is inherently needed and indispensable when evaluating MCD (or any CES service). At the same time, quantitative tools for evaluation are needed to systematically assess and compare outcomes of CES in different contexts where CES services are applied. Yet, empirically sound methodologies in this field of research are scarce.

Therefore, in 2014, the Euro-MCD Instrument was developed to collect outcomes of MCD, by focusing on the perspectives of MCD participants. It contains a list of 26 possible MCD outcomes, classified in six domains: 1) Enhanced emotional support, 2) Enhanced collaboration, 3) Improved moral reflexivity, 4) Improved moral attitude, 5) Impact on the organizational level and 6) Concrete results. This list of outcomes was based on a literature review and further developed with a Delphi panel and content validity testing. For each outcome, respondents are firstly asked to rate the perceived

importance of each outcome, to see whether they recognize the predefined outcomes and how they prioritize the outcomes. This information is important in order to give voice to the MCD participants, as emphasized before. Furthermore, this information might help to tailor the MCD session to the participants' perceptions and expectations. Secondly, respondents are asked to rate whether they have experienced the outcomes, both during the MCD sessions and in their daily work. As such, the instrument explicitly distinguishes between experiences *during* and *after* MCD, hence, it also assesses the self-reported impact of MCD on actual healthcare practice. After the presentation of the Euro-MCD Instrument, field studies were set up to use and further validate the instrument. This thesis presents five field studies to use, test and improve the Euro-MCD Instrument.

Chapter 2 describes a Dutch field study that used the Euro-MCD Instrument in 12 healthcare institutions (nursing homes, psychiatry settings, hospitals and care institutions for mentally disabled people). The aim of this field study was to describe healthcare professionals' perceptions on the importance of outcomes of MCD, before they actually took part in the MCD sessions. In total, 331 healthcare professionals completed the Instrument, and 13 of them were interviewed to gain a more in-depth understanding of their perceptions. Findings show that especially outcomes related to team collaboration were prioritized, and, in a lesser extent, outcomes related to concrete actions. This is in line with previous evaluation studies and literature on goals of MCD, in which aspects related to collaboration are emphasized, like open communication and a shared understanding of the situation. Interviewees further mentioned outcomes about quality of care, which were missing in the original Euro-MCD. This already indicated a first point for reconsideration of the Euro-MCD Instrument.

In **Chapter 3**, a European field study is presented that also aimed to describe the perceived importance of MCD related outcomes, and to assess differences in their perceptions among countries, professions and healthcare settings. Responses to the Euro-MCD Instrument were collected from a larger group of healthcare professionals. In total, 703 healthcare professionals from the Netherlands, Norway and Sweden completed the instrument prior to participation in MCD sessions. Findings showed that the majority of them (more than 76 percent) rated all outcomes in the Euro-MCD Instrument as 'quite' or 'very' important, and that outcomes referring to collaboration and concrete results were perceived as most important. In the open answers to the Instrument, outcomes referring to interaction with patients and their families emerged as a potentially new domain. This was taken into account when further interpreting, discussing and revising the Euro-MCD Instrument.

Next, when comparing responses among subgroups, it turned out that the Norwegian and Swedish respondents rated most outcomes as more important than the Dutch respondents. Furthermore, findings showed that women, older respondents, and professionals not working as a physician gave significantly higher rates than the other respondents. The reasons for these differences were unclear. It might be that cultural differences played a role here (for instance that Scandinavian respondents are more likely to rate the extremely positive answer options). Another possible reason was that Swedish and Norwegian respondents did not yet experience any opportunity for ethical guidance or group reflections and thus were in need of a forum like MCD, whereas these options might be more established in the Netherlands (like group supervision meetings in psychiatry or for physicians). Findings indicated and confirmed the need for a comprehensive instrument, leaving room for a specific focus by different groups of respondents.

The question on perceived importance is further studied in **Chapter 4**, which presents the answers *after* participating in multiple MCD sessions compared with the answers *before* participation. In this study, 443 healthcare professionals from Sweden, Norway and the Netherlands completed the Euro-MCD Instrument after four sessions, and 247 professionals after eight sessions. The majority of them (more than 69 percent) rated all outcomes as 'quite' or 'very' important both *before* and *after* participation in MCD. Outcomes about collaboration, moral reflexivity and moral attitude were rated highest. These findings confirmed the relevance of outcomes in the Euro-MCD Instrument. There was no meaningful difference in ratings when comparing the answers from *before* participation with those *after* participation, suggesting that it does not matter when perceived importance of MCD related outcomes is asked. Nevertheless, considering the overall high rates, the added value of the question on perceived importance became doubtful. Therefore, this question needed reconsideration.

In addition, chapter 4 describes the item structure of the answers to provide insight into possible categorization of outcomes and inform about possible item reduction, with use of factor analyses. Factor analyses did not confirm the predefined six domains but suggested three categories. These categories seemed to represent – to some extent – the following domains from the Euro-MCD Instrument: 'Improved moral reflexivity'; 'Enhanced collaboration'; and a combination of 'Improved moral attitude' and 'Enhanced emotional support'. The categorization of outcomes was taken into account when revising the instrument.

In **Chapter 5**, the item structure of the instrument is also described, but now focused on the *experienced* outcomes, during the MCD sessions and in daily practice. Factor analyses revealed four categories of outcomes. Outcomes referring to virtues, skills for ethical analysis, sharing feelings and actions seemed to cluster together. These categories did not confirm the original division into six Euro-MCD domains. Yet, some similarities could be noted, for instance, the Euro-MCD domain 'Improved moral attitude' was again closely linked to the domain 'Enhanced emotional support'. Factor analyses further showed that items in the domains 'Enhanced collaboration', 'Impact on organizational level' and 'Concrete results' did not clearly associate with each other and might thus not be referring to the presupposed domain. These findings were very helpful for further reflecting on and revising the Euro-MCD Instrument.

Next to examining the item structure, chapter 5 assesses the self-reported experienced outcomes of MCD participants. These responses were collected after four and eight MCD sessions and were related to both the MCD sessions and daily practice. After four and eight MCD sessions, the 443 respectively 247 responding healthcare professionals reported having experienced outcomes referring to collaboration, moral attitude and moral reflexivity *during* the sessions. This impact of MCD on both group as well as individual moral learning is in line with the features of MCD. Considering experienced outcomes in *daily practice*, respondents rated all outcomes as experienced to a significantly lower extent than *during MCD sessions*. It might thus be that positive experiences with MCD sessions do not necessarily lead to equally positive experiences in daily practice. This confirms the relevance of distinguishing between these two settings, which was taken into account in the further process of revising the Euro-MCD Instrument.

Chapter 6 presents another field study. The aim of this study was to define and categorize MCD outcomes in a systematic way, with experienced MCD participants in the Netherlands. The participants (N=12) came from a variety of professional backgrounds and diverse healthcare settings. They took part in two focus group sessions which were structured with the method of Concept mapping. The Euro-MCD Instrument was not taken as a starting point, but served as additional input. Focus group members were first asked to think of and brainstorm about possible MCD outcomes, after which additional possible outcomes from the Euro-MCD Instrument were presented and discussed. The brainstorm resulted in a list of 85 possible MCD outcomes, of which 17 came from the additional Euro-MCD input. Secondly, focus group members were asked to individually categorize these outcomes in (for them) meaningful categories. Based on these individual categorizations, point maps and concept maps

were constructed, which were discussed with the focus group members in order to reach consensus on final categories. Eight categories were defined: 1) Organisation and policy, 2) Team development, 3) Personal development focused on the other person, 4) Personal development as professional, focused on skills, 5) Personal development as professional, focused on knowledge, 6) Personal development as an individual, 7) Perception and connection, 8) Concrete action. When comparing these categories with the original Euro-MCD Instrument, some Euro-MCD domains were easily recognized, like Concrete results or Impact on the organization. Furthermore, a division between the individual level, group level and organizational or case level could be recognized. Findings formed a valuable contribution to further reconsidering and re-categorizing the Euro-MCD Instrument.

Finally, **Chapter 7** presents the Euro-MCD 2.0 and describes the process in which this revised instrument has been developed. Decisions on the outcomes in this instrument were not based on empirical findings alone. These decisions not only required a thorough interpretation of all findings, but also input from theoretical viewpoints on goals of MCD and CES in general. A continuous and balanced dialogue was therefore essential to select the theoretically justified and empirically sound list of MCD related outcomes. This dialogue, described in chapter 7, integrates the empirical findings from previous chapters with theoretical reflections from the research team members and input from European experts in CES and ethics theory. The empirical findings, including an additional field study among Swedish managers, served as a source for the dialogue by indicating points for discussion and suggesting possible re-categorization of outcomes. During this dialogue of several rounds, research team members individually wrote proposals for revision which were then thoroughly discussed, until final agreement was reached on the revised Euro-MCD Instrument: the Euro-MCD 2.0. The revision process was an intense and pioneering exercise as there was no clear protocol on how to develop and revise a measurement tool in this particular research field of evaluation of CES.

As mentioned before, Chapter 7 also presents the result of the revision process: the Euro-MCD 2.0. The revised instrument consists of 15 items, categorized into three domains: Moral competence, Moral teamwork and Moral action. Moral competence entails items on moral sensitivity, analytical skills and a virtuous attitude. Moral teamwork includes items on open dialogue and supportive relationships, and Moral action consists of items on moral decision-making and responsible care. The original items and domains can still – to some extent – be recognized in the revised version. For instance, several items from the former domain of ‘Enhanced collaboration’ can be

found in the new domain 'Moral teamwork'. Next to changing items and domains, the answer options, sentence structure and context of outcomes have been reformulated. The question on perceived importance is no longer part of the instrument. Respondents to the Euro-MCD 2.0 will now be asked to rate their agreement for experiencing each outcome, either regarding the *MCD sessions*, or with regard to *daily practice*.

In the end, the Euro-MCD 2.0 is shorter and less complex than the original Euro-MCD Instrument, and items and domains are more strongly substantiated by empirical findings, theoretical reflections and input from experts and research participants. The revision process has strengths and limitations. We hope it can function as an example on how to use, test and improve an evaluation tool in the research field of CES. Parts of the Euro-MCD 2.0 Instrument might be useful for the evaluation of outcomes of other forms of CES as well. The Euro-MCD 2.0 can now be used to assess outcomes of MCD in various healthcare settings in order to monitor, professionalize and optimize MCD as supportive service for healthcare professionals.