International Journal of Ethics Education (2024) 9:79–104
https://doi.org/10.1007/s40889-024-00185-1

An empirical investigation into moral challenges of (breaching) confidentiality and needs for ethics support when facilitating moral case deliberation

W. M. R. Ligtenberg[1] · A. C. Molewijk[1,2] · M. M. Stolper[1]

Accepted: 14 February 2024 / Published online: 21 March 2024
© The Author(s) 2024

Abstract

Ethics support staff help others to deal with moral challenges. However, they themselves can also experience moral challenges such as issues regarding (breaching) confidentiality when practicing ethics support. Currently there is no insight in these confidentiality issues and also no professional guidance for dealing with them. To gain insight into moral challenges related to Moral Case Deliberation (MCD), we studied a) beliefs and experiences of MCD facilitators regarding breaching confidentiality, b) considerations for (not) breaching confidentiality, and c) needs for an ethics support tool. Data collection consisted of qualitative research methods: six semi-structured interviews; analyses of a) two recorded MCD sessions, and b) a focus group with MCD facilitators. Findings: MCD facilitators mention different conceptions and interpretations of confidentiality and various moral challenges. Questions concerning confidentiality ultimately cause reflections on roles and responsibilities of facilitators. Needs for ethics support vary from seeking advice to procedural and sometimes normative guidance for MCD facilitators. Education for MCD facilitators should focus on developing a concrete tool that stimulates awareness and reflection(skills).

Keywords Confidentiality · Breaching confidentiality · Moral case deliberation · Ethics support tools

✉ W. M. R. Ligtenberg
w.m.r.ligtenberg@amsterdamumc.nl

1 Department of Ethics, Law & Humanities, Amsterdam UMC, Amsterdam, The Netherlands

2 Center for Medical Ethics, Oslo, Norway

Background

Clinical ethics support (CES) consists of various ways to support (health care) professionals in reflection on ethically difficult situations in their work. There are various forms of CES, each with their own approach, goals, and function (Molewijk et al. 2016a; Rasoal et al. 2017). Moral Case Deliberation (MCD) is a specific form of CES facilitated by a trained facilitator (Stolper et al. 2015) and structured by means of a specific conversation method such as the Dilemma Method or the Socratic Dialogue (Molewijk et al. 2008; Steinkamp and Gordijn 2003; Stolper et al. 2016). MCD is grounded in the approach of pragmatic-hermeneutical and dialogical ethics which means there is a strong focus on learning from different viewpoints based on a critical yet constructive moral inquiry (Metselaar et al. 2015; Molewijk et al. 2008). MCD is a common and much-used form of ethics support in the Netherlands, Sweden and Norway (Dauwerse et al. 2014; Grönlund et al. 2016; Hem et al. 2015; Lillemoen and Pedersen 2015; Svantesson et al. 2008; Svantesson et al. 2018).

MCD has no legal status in the Netherlands, and no specific code of conduct to rely on as a facilitator MCD when confronted with professional moral challenges, except to keep professional secrecy or doctor-patient confidentiality (Gevers 2001). Other professional codes of conduct, provided by the employer or related to the professional role of the facilitator e.g. paramedics or pastoral caregiver, might play a role as well but clear guidance about their status in the context of MCD is lacking, which leads often to individual decisions in dealing with these kind of moral challenges. However, as part of the preconditions for MCD both participants and facilitators of MCD usually commit to confidentiality of any information shared during the session (Abma et al. 2009). Confidentiality is kept to make sure participants in MCD can rely on the agreement that all information shared in a MCD session is kept confidential (Agyapong et al. 2009). This commitment stresses the importance of trust in order to ensure an open dialogue and a safe environment in which one can share moral doubt and to collectively explore different courses of action in a specific morally difficult situation (Abma et al. 2009; Metselaar et al. 2015). If confidentiality of an MCD session is not ensured, there is a risk of damaging the (social) safety and trust in the group. Breaching confidentiality can obstruct the space of speaking freely and openly with each other, which is essential in order to learn as a professional (through making mistakes and discussing doubts) individually and as a group or team.

Although the relevance of the commitment to confidentiality is clear to most MCD facilitators, in some circumstances it may occur that MCD facilitators feel compelled to breach confidentiality. From practice we know examples of MCD facilitators themselves that experienced moral challenges related to (not) breaching confidentiality while providing ethics support. For example, if participants in MCD decide upon illegal actions; despite general rules and obligations about reporting illegal actions there are grey zones in health care practice that evoke moral challenges. Or when external parties, like the Health Inspectorate, a manager or supervisor, ask the MCD facilitator to report about what has been discussed during an MCD. Although in principle MCD facilitators do not share information without

explicit and unanimous consent of the MCD participants, there can be situations where the MCD facilitator experiences moral doubt.

A first exploration of the literature yielded little information about the prevalence of moral challenges concerning confidentiality among CES professionals and no information on MCD facilitators specifically. We also did not find any specific normative guidance for how to deal with these moral challenges. With the maturing practice of MCD and the increasing number of trained MCD facilitators, nationally and internationally, we observed a growing need for clarification of the concept of confidentiality within MCD practices (what it is and how it is used), including possible reasons for (not) breaching confidentiality, and a need for theory, policy, guidelines or ethics support for those who are confronted with these challenges. These insights could help in training and supporting (future) facilitators MCD, since current training programs or courses hardly pay attention to this topic.

Since there is not much theoretical research and knowledge about moral challenges related to confidentiality within CES we aim to empirically explore these moral challenges and the needs for support of MCD facilitators by means of three research questions: 1) How do MCD facilitators understand and use the concept of confidentiality in the context of MCD?; 2) What kind of moral challenges related to (breaching) confidentiality do they experience?; and 3) What are MCD facilitators' needs for ethics support and education when they experience these moral challenges? Although this study focusses specifically on MCD, insights and findings might be relevant for confidentiality in a broader CES context. Moreover, the focus on needs for support and education contributes to professionalizing and supporting CES staff and looks at how the theme of confidentiality should be discussed in training and further education of CES staff.

The concept of confidentiality in health care and clinical ethics support

Confidentiality in health care

Confidentiality is a central concept in health care, which has its roots in the Hippocratic Oath and is still central in current codes of medical ethics (Saunders 2020). It is based on two main principles: mutual confidence in the physician–patient relationship and public confidence in the medical profession (Safken and Frewer 2007). There are different views on the status and implications of confidentiality in health care. The debate is whether confidentiality should be a strict principle or a convention in practice (Thompson 1979). Kottow mentions different reasons for breaching confidentiality, such as paternalistic breaching, breaching because of potential danger for others, or breaching because of institutional or public interest, but concludes that they do not outweigh the negative consequences of breaching, which damages the (clinical) encounter (Kottow 1986). Emson argues in favor of confidentiality as a modified value which should be weighed against other relevant values, for example public values or the rights of innocent others (Emson 1988).

Some aspects of confidentiality in health care, specifically practical aspects like confidential handling of patient records, is laid down in national and international laws such as the Health Insurance Portability and Accountability Act (HIPAA) and the AMA code of ethics in the US (Baker 1999; Scott 2000) and the General Data Protection Regulation in the EU (Hoofnagle et al. 2019). The privacy of patient data is generally accepted and all professionals in health care, also MCD facilitators, need to adhere to this commitment.

The role of codes of conduct in various professions

Multiple professions like lawyers, priests, counselors and healthcare professionals often follow a code of conduct that addresses ways to deal with confidential information. This is mostly legally and professionally recorded in an oath or disciplinary law. However, specific codes of ethics do not always provide clear guidance to professionals on how to act or what to adhere to in specific situations. Often there is still room for different interpretations and sometimes professionals have questions whether to follow the code or how to integrate the code of conduct in their professional ethos (Evans et al. 2023). Sometimes the code even conflicts with personal ethical attitudes or values or exceed their initial aim (Jackson et al. 2011; Wiener 2001).

Confidentiality in international clinical ethics support

Clinical ethics support services are provided within different national contexts and (healthcare) systems, which leads to different characteristics in CES systems internationally. For example, Clinical Ethics Consultation (CEC) is a dominant form of ethics services offered in the United States, whereas MCD is a fairly predominant form provided in some northern European countries. National and international law and the history of developments in health care systems shape the context in which confidentiality measures are provided, within the health care system and in CES specifically.

In the United States there have been numerous attempts to develop a code of ethics for bioethicists (Baker 2005; Brody et al. 2007; Latham 2015; Yarmolinsky 2016). These attempts are not without critique, and many authors offered suggestions (Beauchamp 2005; Davis 2005; Miller 2005; Morin 2005; Regenberg and Mathews 2005; Schwab 2016). Most of the codes of ethics contain a section on respecting privacy and maintaining confidentiality and trust. For example, CEC should never exploit information entrusted to them for personal gains (Baker 2005). These codes are mainly intended to deal with cases in which CEC experience conflicts of interest or conflicts of obligation, and when they should balance obligations to maintain confidentiality with other obligations, for example protecting life or preventing serious harm (Schwab 2016). The formulation of these codes of ethics for ethicists is part of a broader discussion on the role, responsibility and accountability of CES staff (Finder and Bliton 2014; Gasparetto et al. 2018; Reiter-Theil 2009; Weise and Daly 2014). Kuperberg and Dauber (2023) recently elaborated on

whether whistleblowing or resigning are acceptable ways for CEC to address clinical misconduct and proposed different criteria for internal and external whistleblowing and resignation (Kuperberg and Dauber 2023).

In northern European context some German papers describe confidentiality in CES (Neitzke 2007; Simon 2021; Simon et al. 2021). However, these papers focus primarily on the protection of the privacy of patient data in CES and not on the moral challenges of CES staff as such. Neitzke (2007) describes how clinical ethics committees should be seen as an integral part of patient care. Recently, Simon et al. (2021) studied perspectives on confidentiality in 'Klinische Ethik Beratung'. Like Neitzke, they suggest that CES should be seen as part of patient care and should thus be made transparent for the patients, including appropriate documentation of the CES within patient files.

Results of informal consultation of European ethics support staff

Prior to our study, we consulted 11 ethics support researchers in Europe via The European Clinical Ethics Network (Molewijk et al. 2016b) and asked them about their experiences with moral challenges related to confidentiality, and their knowledge of the existence of moral guidelines on how to act upon such moral challenges. Their responses, both via email and orally, included only a few experiences with morally difficult cases regarding breaching confidentiality in ethics support, and subsequent reflections on the professional role and responsibilities of CES members. In addition, they reported that, currently, there is no specific formal policy or guideline for CES staff on how to act when experiencing a moral challenge related to confidentiality in ethics support. Also, for MCD specifically, there reported that they were not aware of any specific viewpoint/policy or guidance when a facilitator experiences morally challenging situations in terms of breaching or not breaching confidentiality. Also, according to our knowledge, within (inter)national training and certification of MCD facilitators there is no specific attention for (how to handle) moral challenges related to confidentiality.

Methods

Research design

To gain more insight and explore the depth, richness, and complexity of MCD facilitators' moral challenges related to confidentiality in the context of MCD, we used a descriptive qualitative research design (Rodriquez and Smith 2018). This design allows to combine several research methods (Fig. 1), each with a specific lens to explore; the sequence of the (type of) methods has been carefully considered aiming an additional and enriching in-depth research path. First, we conducted semi-structured interviews to get some insight into the experiences and moral challenges of MCD facilitators. We also facilitated two MCD sessions with Dutch MCD facilitators, both from a national network and from an academic hospital, and used the

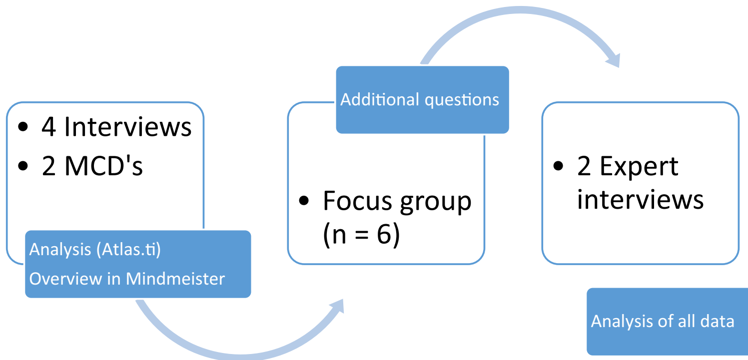

Fig. 1 Elements of data collection

sessions as a research method, in order to get a deeper insight in the moral reasoning and considered actions of MCD facilitators in cases of questions about (breaching) confidentiality. Secondly, we organized a focus group followed by two expert-interviews. We used both methods to examine and reflect in-depth upon the findings gathered from the interviews, literature study and MCD sessions, in order to put these initial results in the context of confidentiality in health care in general.

Both the interviews, the MCD sessions and the focus group were based on and illustrated with concrete cases from MCD practices. We designed the research process in line with the responsive evaluation approach, in which stakeholders are closely involved during the process of data collection and data analysis (Abma and Widdershoven 2014; Abma et al. 2009).

We used a central mind map (in Mindmeister) to create a thematic overview of the central concept and its related concepts and themes. In this mind map insights from different data sources were integrated thematically. For example, statements from respondents of the interviews and MCDs were included in the mind map and were then used in a focus group to further examine and to relate them with experiences and ideas about the concept of confidentiality. The mind map contained an ever-expanding overview of the concept of confidentiality, which was developed throughout the research process. As we describe the different elements of the data collection, we will also refer to this mind map more in depth.

Data collection

Interviews

Semi-structured interviews were conducted with 4 experienced MCD facilitators with diverse professional backgrounds (see Fig. 2). The interviews lasted 40–60 min and the following topics were discussed: the concept of confidentiality, experiences with confidentiality in MCD, experienced moral challenges concerning breaching confidentiality, reflections on actions considered or taken, needs for policies or platforms to discuss questions concerning confidentiality,

Interviews	MCD	Focus group	Expert Interviews
Ethicist (15 years)	Ethics support coordinator (5 years)	Staff member of association of healthcare providers (10 years)	Legal expert
Physician (5 years)	Researcher/teacher (7 years)	Researcher/trainer (9 years)	Confidentiality Counsellor
Physician (10 years)	Researcher/teacher (12 years)	Psychologist (10 years)	
Human Resource Advisor (2,5 years)	Researcher/teacher (4 years)	Researcher/teacher (3 years)	
	Researcher/teacher (9 years)	Physician (8 years)	
	Researcher/teacher (3 years)	Researcher/teacher (3 years)	
	Psychiatrist (7 years)		
	Psychologist (8 years)		
	Clinical ethics supporter (8 years)		
	Trainer (7 years)		
	Philosopher (25 years)		
	Ethics support coordinator (9 years)		
	Ethics support coordinator (3 years)		
	Psychiatrist (4 years)		
	Spiritual care giver (7 years)		

Fig. 2 Overview of research participants' professional background and years of experience as MCD facilitator

and ideas on principles that should be part of a guideline on breaching confidentiality (Appendix 1). Respondents provided answers based on their own experiences, but also shared hypothetical thoughts on situations that might occur in the future.

Additionally, we also conducted two expert interviews concerning confidentiality in health care, one with a legal expert and one with a confidential counsellor. The aim of these additional interviews was to gain more insight in the role of legal aspects of confidentiality in health care, and to learn more from other professional standards in dealing with confidentiality within an academic hospital.

Moral case deliberation as research method

The use of MCD sessions as a research method is rare and mainly used to study the content of MCD and its processes retrospectively (Schaap et al. 2023; Span-Sluyter et al. 2018; Svantesson et al. 2018). In our project we wanted to study the variety of beliefs, values, and principles of the participants concerning confidentiality, as well the variety of considered options for action(s) when breaching confidentiality. That is why we used this kind of moderated group discussions for our data collection. These MCD sessions were purposefully organized by the researchers and both case owners were invited to share their case based on its relevance to the topic of our research.

Both MCD sessions were facilitated by one of the two researchers who were also certified MCD facilitators and MCD trainers, within each session a different facilitator, using the same structured conversation method, i.e., the dilemma method (Molewijk et al. 2008; Stolper et al. 2016). The main differences between MCD and a regular focus group are: 1) in a MCD session the moderated group discussion is relatively more structured by means of a stepwise method (e.g. by using the dilemma method); 2) the focus in MCD is explicitly on individual perspectives of participants, their values, norms and considered courses of actions; and 3) usually in MCD only one case and one central moral questions is reflected upon in detail; 4) usually a focus group aims to gaining or to harvesting insights in participants' experiences and their opinions by means of a discussion instead of fostering mutual understanding by means of a dialogue like in MCD.

Only experienced MCD facilitators participated in both sessions and due to Covid restrictions both sessions were conducted online. The sessions were conducted with different respondent groups to study the different dilemma's that might come with the context practicing MCD. In the first session seven senior facilitators from an academic hospital participated. In the second session eight senior MCD facilitators from a national network participated. All facilitators had followed the same MCD facilitator training and are facilitating MCD in all kinds of (healthcare) institutions and organizations in the Netherlands.

Focus group

Due to the Covid-restrictions the focus group was organized online. The meeting, moderated by the three researchers, was about interpreting and categorizing the results from the literature, the interviews and the MCD sessions (member check). The participants (n = 6) were all experienced MCD facilitators, represented different professional backgrounds (Fig. 2). After introducing the goal of the meeting, we used a 'Mindmeister' mind map to present the different themes and questions in a comprehensible way to the participants. Clarification questions as well normative questions e.g., 'What exactly is breaching confidentiality?' 'When are you allowed to breach confidentiality?' and 'How do you do this in a correct way?', were part of the reflection process. Next, we introduced a statement on the role of the MCD facilitator (*It is not the task or responsibility of the facilitator to change wrongdoings in (healthcare) practice*), reflected on situations that might lead to doubts about

confidentiality in MCD and explored potential courses of action. In the last part of the meeting, we discussed which kind of needs for ethics support they would prefer in the future when confronted with moral challenges.

Selection criteria respondents

Experienced MCD facilitators were included if they had been active as MCD facilitator for at least a few years (5>years; unless large experience was shown otherwise) and facilitate at least 10 MCD sessions every year (see Fig. 2). Participants were approached personally and invited via email.

Data analysis

The interviews were recorded, transcribed and open coded using Atlas.ti (Hwang 2008). These codes were clustered around four categories: 1) concepts, definitions, and descriptions; 2) argumentation, reasons, and values; 3) actions, good behavior; and 4) needs and expectations for an ethics support tool. All interviews were analyzed by the junior researcher. To increase the inter-rater reliability both senior researchers analyzed each two interviews separately and compared their coding with the codes of the junior researcher. In case of disagreement the codes were discussed among the three researchers.

In both online MCD sessions, we used 'Google Jamboard' as a whiteboard to collect values, norms, and individual positions of the participants. While using this interactive tool, the notes were written without personal traceable information. Both the verbal input during the MCD session and the notes on 'Google Jamboard' were anonymized, summarized and included as study data. To stimulate the interaction during the online focus group, we made use of 'Google Jamboard' and 'Mindmeister'. Both programs made all participants, including the moderator, being able to online read and respond at the same time. The audio of the focus group was recorded and together with the responses in 'Google Jamboard' summarized in bullet points with some illustrating quotes.

The codes from the interviews and parts from the summaries of the MCD sessions and the focus group were all integrated into a thematic mind map using the program of Mindmeister (Tummons 2014). This mind map contained an ever-expanding overview of the concept of confidentiality and its accompanying concepts and themes. These codes and concepts and their connections were discussed among the three researchers and were derived through an iterative process of several research meetings. The overview in the mind map served as a tool to present the data during the focus group meeting and meetings among the researchers. The main categories of the mind map also provided a structure for the description of our results.

Research ethics

According to the Ethical Review Board of Amsterdam UMC, a formal ethics approval was not needed according to the Dutch Medical Research Involving Human

Subjects Act (WMO). All methods were performed in accordance with the relevant guidelines and regulations. Written informed consent was obtained from all participants and participation was voluntary and based on informed consent. All respondents received an information letter stating information about the study. This included information in which we emphasized the voluntariness of their participation, their possibility to withdraw from the study without giving reasons, and the anonymity of the data.

Findings

Based on the analysis of the interviews, MCD sessions and the focus group meeting we categorized findings into five categories. The first category is about the concept of confidentiality. The second category is about the role conception of MCD facilitators. The third category contains a description of considerations for breaching confidentiality, whereas the fourth category is about considerations regarding courses of action in case of breaching confidentiality. The final category is on ethics support needs.

1. The concept of confidentiality in MCD

Descriptions of the concept

Respondents often mentioned that what is discussed in MCD will remain private; '*it will remain between us*' (Interview MCD facilitator/ethicist), '*everything stays in this room*' (Interview MCD facilitator/ Human Resource Advisor). Or as a respondent explained:

> *"We agreed that in principle everything that is shared within moral deliberation remains and stays in that room and that people should be able to speak freely without being concerned that their opinion or ideas, their norms and values, together with their names and details, will become known outside that circle"*. (Interview MCD facilitator/physician)

In the MCD sessions, according to the respondents, confidentiality in MCD was often associated with concepts such as 'secrecy' (not talking about individual perspectives or traceable facts from the case), 'trust' (confidentiality as a promise that will be kept by all participants in MCD) and 'reliability' (being reliable and trustworthy in correctly handling personal information).

Goals and challenges of confidentiality in MCD

Respondents mentioned that agreements about confidentiality are meant to create transparency and that they contribute to a safe environment. They mentioned the importance of the MCD process being open, frank, sincere and authentic, and that this requires the preconditions of security and confidentiality. Confidentiality

agreements promote '*free speech*' (Interview MCD facilitator/physician) and in this way contribute to the content, depth, and quality of an MCD.

> *Confidentiality means that everyone should feel the space and freedom to say what they think. The role of a confidentiality agreement is that ultimately everyone participates and everyone's contribution is relevant. Then the goal of MCD is achieved: namely to make a very complex decision together.* (Interview MCD facilitator/physician)

Some limits or disadvantages of keeping confidentiality in MCD has been brought up by the respondents. One respondent mentioned that if one cannot share anything from an MCD, this would mean that also valuable insights and harvest of the MCD cannot be shared, with the loss of creating impact as a consequence. Another participant spoke of the risk of discussed matters being '*covered up*' and losing the benefits of the case discussion.

> *If we [facilitators and participants of the MCD] cover all this up because its confidentiality, then you will simply lose the benefits of the moral deliberation. And you may harm other patients who can end up in the same dilemmas and who are not discussed in a moral case deliberation.* (Interview, MCD facilitator/physician)

Some participants mentioned that a strong focus on confidentiality might eventually be counterproductive and could paradoxically lead to an unsafe atmosphere. For example, emphasizing that you as a facilitator only will breach confidentiality if really necessary, can create an over-awareness among the participants about what to say- they might feel restricted in speaking up at all.

Objects of confidentiality

Answering the question *what* exactly should be kept confidential less agreement was showed among respondents. One respondent specifies: '*nothing will be released (e.g., the report or certain actions) without everyone's consent*' (Interview MCD facilitator/ethicist). Whereas others made suggestions about what to share from an MCD without breaching confidentiality: *'That you participated, others that participated, your own experience, lessons learned, or in a general sense what the tenor was more or less.*' (Interview MCD facilitator/ Human Resource Advisor) Most respondents would agree on sharing the generalized subject, tenor or central theme and results or actions in response to the MCD. Some would also share the values and norms mentioned in the MCD session.

Keeping confidentiality can relate to both the content and the process of the MCD. As a broad consensus, most respondents mentioned that discussing or sharing information about the content of the MCD with people who were not present in the MCD session, and mentioning names and surnames, would be considered breaching confidentiality.

> *It's only when I say, 'in that department they plan to do this and that', or more specifically; 'participant so-and-so is planning to do this and that'. If*

it's traceable, then it's [confidentiality] breached. (Interview, MCD facilitator/human resource specialist)

Aspects concerning the content that should not be shared according our respondents were information on patients or the content of the discussed case and any substantive information that can be traced back to a person. This also includes individual positions of the participants.

I think the confidentiality is also in the fact that an individual point of view and attitude towards the problem is mostly not revealed. And as far as I'm concerned, the conclusion should be reported. But it must be a short and concise conclusion, in which what has been said cannot be traced back to a person. (Interview, MCD facilitator/physician)

With regard to the process, one respondent mentioned the importance of confidentially regarding participants' 'thought processes' and the development of individual perspectives as well.

There is great vulnerability in expressing your (developing) thoughts, which is also part of confidentiality. [About MCD:] "This is a place where you can shape your thinking, so you should be able to speak freely and frankly." (Focus group, trainer of MCD facilitators)

Consequences of breaching confidentiality

Most respondents were initially hesitant to talk and think about possible ways of breaching confidentiality since they experienced a high threshold to consider taking actions on something that happened or was said during an MCD. Either they never experienced a situation that generated moral questions about breaching confidentiality, or they considered confidentiality to be the greater good. In the latter situation they preferred to take the burden of keeping confidentiality and ignore their feelings or doubts.

In the responses from European colleagues several potential consequences of breaching confidentiality were mentioned. Moral case deliberation should be '*a safe space for moral doubt*'; if there is the possibility that the MCD facilitator will breach confidentiality, participants may fear a *'moral disapproval'*. As a consequence, being open and vulnerable within MCD might be *'even more threatening'*. Also, the MCD facilitators said that when confidentiality can be breached, MCD participants may not feel free to speak up or consider leaving things unsaid.

The power of MCD is precisely that it can be about anything, that everyone can say anything. [...] What if at some point there will be a tool or […] a requirement/protocol /instruction, what will that do to the impact of MCD? […] (Focus group, MCD facilitator/psychologist)

2. Role conception of MCD facilitators and confidentiality in MCD

In the interviews and focus group, and more specifically in the MCD sessions, respondents related their reflections about (not) breaching confidentiality on their views on the tasks and responsibilities of the MCD facilitator, in general and specifically with regard to safeguarding confidentiality.

In the focus group we discussed the statement: *It is not the task or responsibility of the facilitator to change wrongdoings in (healthcare) practice*. Some said, the task of the facilitator is first and foremost to facilitate the conversation and the process of the MCD.

> *If someone says 'I'm used to misbehaving as a professional', it's not your job to do something about it. It is more important that people share their thoughts and opinions on the matter with each other*. (Interview, MCD facilitator/ethicist)

Respondents mostly agreed that the task of the MCD facilitator is not to change things in practice. However, by asking critical questions, facilitators can stimulate moral reflection and so indirectly contribute to the moral sensitivity of professionals.

> *The basic attitude is having trust in [the reflective capacity of] healthcare professionals, assuming that they can do themselves. The task of the moderator is to awaken, tap into, keep alive and nourish it*. (Focus group, MCD facilitator/ethicist)

This quote illustrates the focus on the goal of (moral) learning in MCD. Facilitators consider their task to ensure that this learning process is realized in the correct way. However, some respondents explained how they experienced a discrepancy between their professional responsibilities as facilitator, which focus mainly on the deliberation process, and their sense of responsibility for the quality of care and other circumstances of the team of MCD participants.

> *As MCD facilitator you are not responsible for what does or does not happen in an organization. Not at all: you are leading a process. Employees are responsible for their own actions. Well, except when you witness something that is prohibited or unacceptable; then you can't say 'I have heard it, but it has nothing to do with me'. No, then, especially as an internal MCD facilitator, I am also responsible for what happens within the organization*. (Interview, MCD facilitator/human resource specialist)

In situations like this, breaching confidentiality was considered, because the facilitator was not entirely clear about what was or was not part of their responsibilities. During the MCD sessions we discussed responsibilities towards one's own reputation and reliability as MCD facilitator *('when my moral compass sounds the alarm, I must take responsibility',* MCD facilitator/psychiatrist), and responsibilities towards the integrity and reputation of 'the institution and the imago of MCD' and towards the organization as a whole.

Some respondents mentioned how issues concerning confidentiality were influenced by the different roles or positions they hold. For example, a respondent who is both an MCD facilitator and a medical doctor:

We know the tricks of the trade; we know what a professional secret is and we know how to act in it because we are doctors. [...] I don't know whether it is equally familiar territory [for MCD facilitators from a different background], to act on the basis of professional secrecy as it is for a doctor, who is already used to doing so. So maybe the answer is really different for others, but I don't have much difficulty with that myself. (Interview, MCD facilitator/physician)

Some respondents made a distinction in facilitating MCD in their organization and in an external organization, and explained that being part (as an employee) of the organization generated a sense of joint responsibility for quality of care in the hospital. This raised moral questions concerning confidentiality and witnessing clinical misconduct. MCD facilitators that operated as external facilitator in another organization experienced different moral challenges concerning their role and responsibilities. For example: Being outsourced, to what extend am I, or should I be, responsible for the content/continuation of the MCD? And: should you justify your decisions regarding breaching confidentiality (even more) because of the outsourcing?

3. Moral challenges related to (not) breaching confidentiality

Initially, respondents thought they did not have many issues or moral challenges concerning confidentiality in MCD, but as they started to think and speak about them in the interviews, the MCD sessions and focus group, they became increasingly aware of them and in the implications for the role of MCD facilitator. In our research, different causes for moral questions about taking action as an MCD facilitator were mentioned.

When safety or wellbeing of a team (member) is at stake

Some considerations regarding breaching confidentiality had to do with individual participants in MCD, for example when their safety or wellbeing is at stake. During an interview one respondent mentioned suspecting one of the MCD participants having a depression or suicidal thoughts. There are also reasons for breaching confidentiality at the team level, for example the observation of an unsafe situation or a problematic team culture.

The moment you, as MCD facilitator, sense that there are issues that make you think the quality of care is compromised, or that this might even lead to unsafe situations, and not just for the patient and for healthcare, but also for the team and for the employees, that this could well be a reason to breach confidentiality. (Interview, MCD facilitator/physician)

Illegal actions

Other considerations were related to the attitudes and intentions of participants in MCD. Respondents mentioned the example of a participant planning to do something illegal:

> *If someone intends to do something that is actually illegal, according to the law, or that is totally inconsistent with our agreements as an organization. Something that goes completely against what we as an organization or department would like to promote*. (Interview, MCD facilitator/human resource specialist)

Threat of the wellbeing of the patient

On a more abstract level there were reasons related to the existence of a concrete, identifiable, avoidable and harmful consequence if confidentiality was kept and no action was taken.

> *You have to have very good reasons for breaching confidentiality. There must actually be a very concrete, identifiable, avoidable, and harmful consequence of not telling, of keeping something to yourself.* (Interview, MCD facilitator/ethicist)

Concerning the content of the specific case discussion, one respondent in the focus group spoke about the observation of deviant care practices as a reason to consider taking action. For example, when the safety or wellbeing of the patient is at stake, especially when '*the person himself is not able to protect his own wellbeing/safety or is ignorant of the abuse that is being committed against him'* (MCD facilitator/trainer).

4. Considerations regarding courses of action when breaching confidentiality might be at stake

Our research showed that it is not always clear to respondents which action or behavior actually constitutes a form of breaching confidentiality. In this paragraph we will discuss the various courses of action that were mentioned by the respondents when they considered breaching confidentiality.

Sharing is caring

Respondents considered actions related to an individual. For example, to contact a participant outside the context of the MCD to discuss your observations or to get the individual participant to take some actions.

> *First addressing it directly, because that's what we stand for in our organization: you talk to each other, not about each other. [...] That conversation with the (MCD) participant is not a breach of confidentiality in my opinion. Letting him know my concern is basically still keeping it among the people who took part in that conversation, the people who know all about it.* (Interview, MCD facilitator/human resource specialist)

Speaking individually with an MCD participant was also seen as a way of preventing or double-checking the breach of confidentiality towards others, outside the MCD context.

Other proposed courses of action were targeted at the group of participants in MCD as a whole. Questions concerning confidentiality can even be made the subject of the MCD session itself, if necessary. Facilitators also considered a meta-conversation during the MCD to share their personal doubts/concerns with the participants, and thus resolve their personal moral concern regarding breaching confidentiality during that MCD session.

Seeking confidential advice about confidential issues

Another set of actions had to do with consulting someone or asking for advice. The mentioned persons or institutions to consult were diverse, varying from a person with whom you have a 'confidentiality agreement' (which is not further specified), a confidential counselor, the manager that requested the MCD, a fellow MCD facilitator, someone from the private sphere, the contact person of the department where the MCD took place, someone from the ethics (support) working group or department, or 'someone higher up in hierarchy'. Other ways of taking action were related to joint reflection. For example, by sharing your (moral) questions in peer meetings with fellow MCD facilitators, or by organizing an MCD on your own moral question.

Implicit steering or following the moral concern at stake

Respondents saw options to implicitly steer or influence the group and the MCD process with respect to the MCD facilitator's specific moral concern. For example, explicitly support teams and pointing out the possibility of approaching a confidential adviser, or to suggest consulting existing protocols or guidelines. Another implicit way of dealing with the MCD facilitator's moral concern is the option of polling the MCD participants whether there is a need for a follow-up MCD. Some respondents were also considering planning an additional joint action as an follow-up, in order to check to what extent the discussed matters are been taken in action.

Follow-up is important and I also feel responsible for this, but ultimately it is up to the organization to take steps in this direction. (MCD session, nursing specialist)

One respondent suggested to write down his/her concerns in the MCD notes, as a way to draw attention to his/her observations. However, during the MCD other respondents objected by saying '*the notes belong to the team, and not to the MCD facilitator'* (MCD facilitator/researcher).

Grey area of actions of breaching confidentiality

Respondents had different viewpoints on whether each of the above-mentioned actions should be considered breaching confidentiality or not. Some even see a continuum of actions between breaching and keeping confidentiality. In order to further explore this variety, we asked MCD facilitators in a focus group for their ideas on which of the proposed actions they would consider breaching confidentiality and which not.

We start by describing the actions upon which the focus group reached consensus. Actions that were definitely not considered breaching confidentiality were: scheduling a follow-up MCD, taking a moment to reflect, pointing out the possibility of a confidential adviser, consulting someone with whom you have a 'confidentiality agreement', to organize an MCD on your own moral question, and supporting the team in their search for solutions. Actions that were considered a breach of confidentiality were: consulting your manager and contacting a participant outside the MCD to discuss your observations or to induce the individual to take action.

There was disagreement on some actions, for example, some respondents do not regard 'discussing with fellow MCD facilitators' as breaching confidentiality, whereas others do. The respondents also disagreed about 'getting advice from (someone)'. Some see this as part of preserving confidentiality. One person indicated that consulting the client who commissioned the MCD was considered an option depending on your own position within the organization, and another mentioned that consulting a confidential counselor was considered breaching confidentiality, but in a morally acceptable way.

5. Needs for ethics support and education

We explored the needs of MCD facilitators for support and education when dealing with possible (moral) challenges concerning (breaching) confidentiality. Some of the respondents mentioned no needs, existing structures were seen as sufficient, e.g., a confidential counselor, a partner or fellow MCD facilitator to discuss their moral challenges with. Others mentioned the need of a moment to reflect, to think about intentions and motivation to (not) breach confidentiality in the specific situation, and to reflect on your role as MCD facilitator and of other people involved. The needs differed between ways to reflect individually

and interpersonal, such as an MCD among facilitators to discuss their moral challenges and questions.

Other respondents suggested different forms of support or education, for example an 'ethics support tool', such as an interactive moral compass (de Snoo-Trimp et al. 2022; Gerritse et al. 2023; Hartman et al. 2019, 2018). Or a platform for guidelines or questions to the community or experts. The latter was based on needs for more knowledge and guidance on how they *should* deal with (moral challenges related to) confidentiality in practice, a more normative and specific framework including guidance on what is expected from them as MCD facilitators. One respondent suggested working towards creating a moral oath for MCD facilitators or a certificate in which the MCD facilitator confirms to uphold certain methods and actions, also concerning confidentiality.

Form and content of a possible ethics support tool

One respondent mentioned during the focus group, a tool should be developed '*to preserve and enhance the power of MCD'* (MCD facilitator/psychologist), because when confidentiality is breached this might do harm to MCD as a practice. When discussing in more detail the idea of an ethics support tool, respondents shared their ideas on the design and content of such a tool. Some wanted it to contain a general baseline for questions concerning confidentiality.

> *I think it's important you try to achieve clear agreements [among facilitators MCD within our institution] about this. That while cases can be very different, that you still have some sort of general grounding. What to do if you find yourself considering violating confidentiality? How can you solve that? And under what circumstances might it be allowed or not allowed?* (Interview, MCD facilitator/physician)

Respondents mentioned that a tool or manual should not consist of airtight agreements on paper, but should initiate learning and reflection about confidentiality:

> *I want to avoid a decision tree at all costs. MCD is the place where people can explore freely, in the company of each other, where also unpleasantness can get discussed. If we lose that, there is no point in doing MCD. I don't want it to be legalized*. (Focus group, MCD facilitator/ trainer)

Others did ask for legal clarification, especially concerning the right of nondisclosure and the (legal) position and protection of MCD facilitators when *not* breaching confidentiality. If there is one thing that MCD facilitators would like to be captured, it would be the freedom to maintain confidentiality.

> *I need something to go back to, that I can point to – something I use to support my decision. One reason that you could confidently say 'I'm not going to take any action' would be a kind of nondisclosure (which confidential counselors and ombudsmen have, as protection). A protected status would be nice, that you are also protected during the time when you are still unsure of your actions or position*. (Focus group, facilitator MCD/teacher)

Respondents also mentioned the idea of a moral compass to help with questions that might come up. For example, when it comes to weighing the public interest and harm versus the harm to an individual whose confidentiality you might breach?

> *I'm thinking of a decision tool that contains all the options you can think of. That you are given themes, so that you can shine a light on things that can play a role, without being directive. That you can then discuss it with others. This also means that the tool can be used in conversation with colleagues*. (Focus group, facilitator MCD/physician)

A final suggestion was to make the subject of moral challenges related to confidentiality part of the training program (or refresher courses) for MCD facilitators.

Discussion

Our research contributes to the knowledge about the concept of confidentiality in MCD and related moral challenges for MCD facilitators. It also induces reflections on the various roles, (legal) status and responsibilities of MCD facilitators which we will address briefly in this paragraph. We will also briefly reflect on the suggestions for needs for ethics support and education for facilitators.

Complexity and prevalence of moral challenges related to confidentiality

This study made clear how confidentiality is a multifaceted concept which is interpreted and valued differently by MCD facilitators. It turned out, in line with our view on ethics (support), that the meaning of the concept of confidentiality is contextual and constructed in interactions. The meaning and the moral value of confidentiality has to be weighed and balanced with other values in each specific situation, together with those involved.

The theme of confidentiality in MCD proved to be much more comprehensive and complex than initially thought and was much more latent than respondents initially expected. At first, it seemed there were not many questions. However, when we introduced the concept in the research process, participants realized the actuality of the topic and became more aware of the importance and relevance of confidentiality in MCD. We think the concept of (breaching) confidentiality and the moral challenges concerning (breaching) confidentiality in ethics support should be more actively discussed during training or refresher courses for both MCD facilitators and ethics support staff in general. The research questions and findings in this study might be of help in structuring such discussions.

The (legal) status of a MCD facilitator and accountability within CES

Many of the moral questions concerning confidentiality were in some way related to the position of the ethics support provider, in particular the MCD facilitator. Is he or she an integral part of patient care? (Neitzke 2007) Or should we see them as

'outsiders' – more separate from daily healthcare practice? What does this mean for the responsibilities of the MCD facilitator? Medical professional secrecy or doctor-patient confidentiality applies to MCD facilitators who are also medical doctors, but there is no legal code of conduct or an oath in terms of professional secrecy for MCD facilitators. Respondents reported they needed more clarity upon this as well on the relation with guidelines and codes of conduct of 'other' professional roles they practice.

In international debates, the experienced accountability of CES staff is explored. The question of the degree of accountability for patient care outcomes was also posed by our respondents. Weise and Daly (2014) suggested that CEC-consultants with a background in clinical practice and its related code of ethics, might perceive a different kind of accountability for practice and patient outcomes than clinical ethics consultants with a different professional background (i.e. not a clinical or caregiver background). They distinguish different forms of accountability: restricted accountability, unbound accountability and they propose the concept of balanced accountability (Weise and Daly 2014). These concepts may be of use for reflecting on questions concerning breaching confidentiality in MCD. For example, CEC with restricted accountability is mainly focused on the process, as it was also mentioned by most of our respondents who stated that MCD facilitators are mainly responsible for the process in MCD. Future research should find out in which the different concepts of accountability might be helpful for MCD facilitators when being confronted with moral challenges about confidentiality.

Finder and Bliton (2014) also reflected on roles, activities, and accountability of clinical ethics consultants. They make a distinction between role-based and activity-based responsibility, and between individual and corporate accountability (Finder and Bliton 2014). This latter distinction is relevant in the case of individuals who combine their role as a facilitator with another institutional role. Lastly, Finder and Bliton (2014) describe the difference between developing an understanding of accountability and the experience of actually being accountable. This may also be applicable to the respondents who described a *feeling* of responsibility towards the outcomes of MCD, without having a clear idea and knowledge about their actual responsibilities as a MCD facilitator. In conclusion, the status and role of MCD facilitators in diverse contexts need clarification and explanation. That also applies to CES staff and CES services in a broader sense.

Differences between MCD facilitator and professional secrecy in health care

Some respondents compared confidentiality in MCD to professional secrecy or doctor-patient confidentiality of healthcare providers. Even if the MCD facilitator does not have a clinical background, such as philosophers and ethicists, they are seen as consultants within the team when facilitating MCDs on patient care. The facilitator is seen as an 'extended arm' of the health care provider which

means he or she need to adhere to the same confidentiality codes of conduct. However, until now there is no formal documentation about this position of 'extended arm' and its responsibilities. Being a MCD facilitator is not a formal profession and MCD facilitators do not have a legal status. At the same time, it is more than just a role. Becoming and being a MCD facilitator includes a formal training and a set of specific competencies (Stolper et al. 2015). More conceptualization and research are needed about the professional role and legal status of the MCD facilitator, which might also help with respect to preventing and dealing with moral challenges related to (not) breaching confidentiality.

Needs for ethics support to ethics support staff

In the Dutch context there is no code of conduct for MCD facilitators. Facilitators often work individually which pleas for a stronger need of an ethics support tool with clarifications, frameworks and alternatives for action(s) in dealing with challenges concerning (breaching) confidentiality.

Based on the findings, we intend to develop an ethics support tool that stimulates the development of knowledge, attitude and skills of facilitators MCD. A tool that provides 1) *information* about the concept of confidentiality in general and in the context of CES, 2) *reflection* and *weighing* questions that guides the facilitator in his/her considerations whether to breach confidentiality or not, and 3) possible *courses of actions* in case of both, breaching and not-breaching confidentiality (Ligtenberg et al. 2024). In general, some kind of ethics support with practical and educational purposes and more clarity about the formal position of MCD facilitators are important for the further professionalization of MCD (facilitators).

Strengths and limitations

Lastly, we reflect on the strengths and limitations of this study. Confidentiality in MCD is a relevant and actual topic that has not thoroughly been researched before. A strong point in this study is the close cooperation with MCD practice, whilst conducting the study, and including MCD facilitators in the different stages of data collecting. Moreover, they were not only the object of study, they also contributed in the analysis by reflecting upon the findings at various moments and stages in the study, and provided new insights. The use of MCD as a method for data gathering can be seen as a strength in this research given the advantages of a structured way of data collection on moral reasoning and the link to concrete actions in practice. We suggest that the use of MCD sessions as an additional research method, should be further developed.

Considering limitations, we should critically reflect upon our role as researcher, conducting research amongst fellow MCD facilitators. Being experienced MCD facilitators ourselves we might unconsciously have influenced the questioning during the MCD sessions or the focus group. Whilst we were aware of this point

– and therefore critically questioned each other during all phases in the research project—our own normative ideas about (the handling of) confidentiality in MCD might have influenced the data gathering and analysis. Besides, almost all participants in this study were in some way related to our ethics support group or another department of the academic hospital (only the focus group also contained some participants from different institutions). This might have created a bias; ideally, MCD facilitators that received a different type of training and whom would have introduced different viewpoints, are also included. Lastly, using online meetings for the interviews, MCD sessions and the focus group limits to foster the dialogue and joint reflection processes compared to real life meetings.

We suggest some approaches for future research. First, it might be interesting to conduct a systematic literature review into experiences and existing normative guidance internationally for CES staff. Secondly, since we only included facilitators in our study, follow-up research can look more into the role and perspective of MCD participants regarding (breaching) confidentiality and specifically at the position of reports (and publication).

Conclusion

In this research we investigated moral themes and challenges concerning confidentiality as experienced by MCD facilitators in the context of facilitating MCD. As a result, a variety of moral challenges has been found, and respondents had different views and understandings of the concept of confidentiality and when it is breached. The results show us how reflections on this concept touches upon different related topics such as the role and responsibilities of the MCD facilitator. We investigated diverse needs of MCD facilitators for ethics support and education in dealing with these moral challenges; both the need for more knowledge in terms of information and clarification, and the need for reflection and guidance in concrete morally challenging situations. These needs including clarity about the role and status of MCD, deserve more attention in training programs or refreshing courses for (trained) MCD facilitators. Findings and suggestions of this study can be relevant for ethics support staff in general. We conclude that a thematic ethics support tool, offering conceptual, reflective and normative guidance in cases of moral challenges around confidentiality, could be helpful.

Appendix 1. Interview topics

- Introduction

  Informed consent
  Demographics
  Experience MCD

- **The concept of confidentiality**

  Meaning
  Function

Possible drawbacks
Difference with other professions?

- **Experiences from MCD practice**

Thoughts
Actions

- **Zooming out**

Reasons for breaching confidentiality
Ways of breaching confidentiality

- **Looking ahead**

Future scenario's
Need for guidance

- **Wrap up**

Final thoughts
Participate in MCD of focus group?

Acknowledgements We would like to thank all participants for their contributions.

Authors' contributions All authors analyzed and interpreted the data. WMRL drafted and wrote the major contribution for the manuscript. Other authors contributed in writing and reading the manuscript. All authors approved the final manuscript.

Funding The authors did not receive any funding for this study.

Data availability The data generated and/or analyzed during the current study are not publicly available but are available from the corresponding author on reasonable request.

Declarations

Ethics review board approval and consent to participate The Ethical Review Board (2020.238) of Amsterdam UMC is informed about this study. Ethics Review Board approval was not needed according to the Dutch Medical Research Involving Human Subjects Act (WMO).

All methods were performed in accordance with the relevant guidelines and regulations. Written informed consent was obtained from all participants and participation was voluntary and based on informed consent. Before the interview, MCD or focus group respondents received an information letter stating information about the study. This included information in which we emphasized the voluntariness of their participation, their possibility to withdraw from the survey study without giving reasons, and anonymity of the data.

Consent for publication Written informed consent for publication was given by all involved participants and researchers.

Competing interests The authors declare that they have no competing interests.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line

to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/.

References

Abma, T., and G. Widdershoven. 2014. Dialogical ethics and responsive evaluation as a framework for patient participation. *The American Journal of Bioethics* 14 (6): 27–29.

Abma, T.A., B. Molewijk, and G.A. Widdershoven. 2009. Good care in ongoing dialogue. Improving the quality of care through moral deliberation and responsive evaluation. *Health Care Analysis* 17 (3): 217–235.

Agyapong, V., R. Kirrane, and R. Bangaru. 2009. Medical confidentiality versus disclosure: Ethical and legal dilemmas. *Journal of Forensic and Legal Medicine* 16 (2): 93–96.

Baker, R. 1999. *The American medical ethics revolution: How the AMA's code of ethics has transformed physicians' relationships to patients, professionals, and society*. JHU Press.

Baker, R. 2005. A draft model aggregated code of ethics for bioethicists. *The American Journal of Bioethics* 5 (5): 33–41.

Beauchamp, T.L. 2005. What can a model professional code for bioethics hope to achieve? *The American Journal of Bioethics* 5 (5): 42–43.

Brody, B., N. Dubler, J. Blustein, A. Caplan, J.P. Kahn, N. Kass, B. Lo, J. Moreno, J. Sugarman, and L. Zoloth. 2007. Bioethics consultation in the private sector. In *Gekauftes Gewissen?* 291–300. Brill Mentis.

Dauwerse, L., M. Stolper, G. Widdershoven, and B. Molewijk. 2014. Prevalence and characteristics of moral case deliberation in Dutch health care. *Medicine, Health Care and Philosophy* 17 (3): 365–375.

Davis, M. 2005. Comments on Baker's "Draft Model Aggregated Code of Ethics for Bioethicists." *The American Journal of Bioethics* 5 (5): 57–59.

de Snoo-Trimp, J., A. de Vries, B. Molewijk, and I. Hein. 2022. How to deal with moral challenges around the decision-making competence in transgender adolescent care? Development of an ethics support tool. *BMC Medical Ethics* 23 (1): 1–15.

Emson, H. 1988. Confidentiality: A modified value. *Journal of Medical Ethics* 14 (2): 87–90.

Evans, N., A. Schmolmueller, M. Stolper, G. Inguaggiato, A. Hooghiemstra, R. Tokalic, D. Pizzolato, N. Foeger, A. Marušić, M. van Hoof, D. Lanzerath, B. Molewijk, K. Dierickx, and G. Widdershoven On. 2023. VIRT2UE: A European train-the-trainer programme for teaching research integrity. *Research Ethics*. https://doi.org/10.1177/17470161231161267

Finder, S.G., and M.J. Bliton. 2014. Accountability and the clinical practice of ethics consultation: Roles, activities, and the experience of doing. *The American Journal of Bioethics* 14 (6): 52–53.

Gasparetto, A., R.J. Jox, and M. Picozzi. 2018. The notion of neutrality in clinical ethics consultation. *Philosophy, Ethics, and Humanities in Medicine* 13 (1): 1–7.

Gerritse, K., C. Martens, M.A. Bremmer, B.P. Kreukels, A.L. de Vries, and B.C. Molewijk. 2023. GenderJourney: participatory development of an ethics support tool to foster dialogue and reflection on shared decision-making in gender-affirming medical care. *Patient Education and Counseling* 114: 107854.

Gevers, J. 2001. Evaluation of the Dutch medical treatment act (WGBO). *Nederlands Tijdschrift voor Geneeskunde* 145 (11): 509–512.

Grönlund, C.F., V. Dahlqvist, K. Zingmark, M. Sandlund, and A. Söderberg. 2016. Managing ethical difficulties in healthcare: Communicating in inter-professional clinical ethics support sessions. *HEC Forum* 28 (4): 321–338.

Hartman, L., S. Metselaar, G. Widdershoven, and B. Molewijk. 2019. Developing a 'moral compass tool'based on moral case deliberations: A pragmatic hermeneutic approach to clinical ethics. *Bioethics* 33 (9): 1012–1021.

Hartman, L.A., S. Metselaar, A. Molewijk, H. Edelbroek, and G.A. Widdershoven. 2018. Developing an ethics support tool for dealing with dilemmas around client autonomy based on moral case deliberations. *BMC Medical Ethics* 19 (1): 1–11.
Hem, M.H., R. Pedersen, R. Norvoll, and B. Molewijk. 2015. Evaluating clinical ethics support in mental healthcare: A systematic literature review. *Nursing Ethics* 22 (4): 452–466.
Hoofnagle, C.J., B. Van der Sloot, and F.Z. Borgesius. 2019. The European Union general data protection regulation: What it is and what it means. *Information & Communications Technology Law* 28 (1): 65–98.
Hwang, S. 2008. Utilizing qualitative data analysis software: A review of Atlas.ti. *Social Science Computer Review* 26 (4): 519–527.
Jackson, D., K. Peters, M. Hutchinson, M. Edenborough, L. Luck, and L. Wilkes. 2011. Exploring confidentiality in the context of nurse whistle blowing: Issues for nurse managers. *Journal of Nursing Management* 19 (5): 655–663.
Kottow, M.H. 1986. Medical confidentiality: An intransigent and absolute obligation. *Journal of Medical Ethics* 12 (3): 117–122.
Kuperberg, E., and M.S. Dauber. 2023. Addressing clinical misconduct: Resigning and whistleblowing in clinical ethics consultation. *HEC Forum* 35 (2): 161–183. https://doi.org/10.1007/s10730-021-09459-3.
Latham, S.R. 2015. Professionalization of clinical ethics consultation: Defining (down) the code. *The American Journal of Bioethics* 15 (5): 54–56.
Ligtenberg, W. M. R., Stolper, M. M, and Molewijk, A. C. 2024. Ethics support for ethics support: The development of the confidentiality compass for dealing with moral challenges concerning (breaching) confidentiality in moral case deliberation. *BMC Medical Ethics.*
Lillemoen, L., and R. Pedersen. 2015. Ethics reflection groups in community health services: An evaluation study. *BMC Medical Ethics* 16 (1): 1–10.
Metselaar, S., B. Molewijk, and G. Widdershoven. 2015. Beyond recommendation and mediation: Moral case deliberation as moral learning in dialogue. *The American Journal of Bioethics* 15 (1): 50–51.
Miller, F.G. 2005. The case for a code of ethics for bioethicists: Some reasons for skepticism. *The American Journal of Bioethics* 5 (5): 50–52.
Molewijk, B., A. Slowther, and M. Aulisio. 2016a. Clinical ethics support. In H. ten Have (Ed.), *Encyclopedia of global bioethics*. Springer
Molewijk, A.C., T. Abma, M. Stolper, and G. Widdershoven. 2008. Teaching ethics in the clinic. The theory and practice of moral case deliberation. *Journal of Medical Ethics* 34 (2): 120–124.
Molewijk, B., A. Slowther, and J. Schildmann. 2016. The European clinical ethics network (ECEN): The professional development of clinical ethics support in Europe and the importance of quality assessment through evaluation research. *Bioethica Forum* 9 (2): 86–89.
Morin, K. 2005. Code of ethics for bioethicists: Medicine's lessons worth heeding. *The American Journal of Bioethics* 5 (5): 60–62.
Neitzke, G. 2007. Confidentiality, secrecy, and privacy in ethics consultation. *HEC Forum* 19: 293.
Rasoal, D., K. Skovdahl, M. Gifford, and A. Kihlgren. 2017. Clinical ethics support for healthcare personnel: An integrative literature review. *HEC Forum* 29: 313–346.
Regenberg, A.C., and D.J. Mathews. 2005. Resisting the tide of professionalization: Valuing diversity in bioethics. *The American Journal of Bioethics* 5 (5): 44–45.
Reiter-Theil, S. 2009. Dealing with the normative dimension in clinical ethics consultation. *Cambridge Quarterly of Healthcare Ethics* 18 (4): 347–359.
Rodriquez, A., and J. Smith. 2018. Phenomenology as a healthcare research method. *Evidence Based Nursing* 21 (4): 96–98.
Safken, C., and A. Frewer. 2007. The duty to warn and clinical ethics: Legal and ethical aspects of confidentiality and HIV/AIDS. *HEC Forum* 19: 313.
Saunders, J. 2020. Confidentiality in medical practice. *Medicine* 48 (10): 644–646.
Schaap, A.I., Molewijk, A.C, and Stolper, M. M. 2023. Moral case deliberation in dutch prisons: Experienced outcomes and the moral learning of prison staff. *European Journal on Criminal Policy and Research*. https://doi.org/10.1007/s10610-023-09562-w.
Schwab, A. 2016. The ASBH code of ethics and the limits of professional healthcare ethics consultations. *Journal of Medical Ethics* 42 (8): 504–509.
Scott, C. 2000. Is too much privacy bad for your health–an introduction to the law, ethics, and HIPAA rule on medical privacy. *Georgia State University Law Review* 17: 481.

Simon, A. 2021. Empfehlungen zur Schweigepflicht und zum Datenschutz in der klinischen Ethikberatung. *Medizinrecht* 39 (4): 345–345.

Simon, A., C. Zang, and F. Nauck. 2021. Patientendaten und Schweigepflicht in der klinischen Ethikberatung-Ergebnisse einer empirischen Befragung. *Medizinrecht* 39: 340–345.

Span-Sluyter, C.A., J. Lavrijsen, E. van Leeuwen, and R.T. Koopmans. 2018. Moral dilemmas and conflicts concerning patients in a vegetative state/unresponsive wakefulness syndrome: Shared or non-shared decision making? A qualitative study of the professional perspective in two moral case deliberations. *BMC Medical Ethics* 19 (1): 1–12.

Steinkamp, N., and B. Gordijn. 2003. Ethical case deliberation on the ward. A comparison of four methods. *Medicine, Health Care and Philosophy* 6: 235–246.

Stolper, M., B. Molewijk, and G. Widdershoven. 2015. Learning by doing. Training health care professionals to become facilitator of moral case deliberation. *HEC Forum* 27 (1): 47–59.

Stolper, M., B. Molewijk, and G. Widdershoven. 2016. Bioethics education in clinical settings: Theory and practice of the dilemma method of moral case deliberation. *BMC Medical Ethics* 17 (1): 1–10.

Svantesson, M., R. Löfmark, H. Thorsén, K. Kallenberg, and G. Ahlström. 2008. Learning a way through ethical problems: Swedish nurses' and doctors' experiences from one model of ethics rounds. *Journal of Medical Ethics* 34 (5): 399–406.

Svantesson, M., M. Silén, and I. James. 2018. It's not all about moral reasoning: Understanding the content of moral case deliberation. *Nursing Ethics* 25 (2): 212–229.

Thompson, I.E. 1979. The nature of confidentiality. *Journal of Medical Ethics* 5 (2): 57–64.

Tummons, J. 2014. Using software for qualitative data analysis: Research outside paradigmatic boundaries. In *Big data? Qualitative approaches to digital research*. Emerald Group Publishing Limited.

Weise, K.L., and B.J. Daly. 2014. Exploring accountability of clinical ethics consultants: Practice and training implications. *The American Journal of Bioethics* 14 (6): 34–41.

Wiener, J. 2001. Confidentiality and paradox: The location of ethical space. *Journal of Analytical Psychology* 46 (3): 431–442.

Yarmolinsky, R. 2016. Ethics for ethicists? The professionalization of clinical ethics consultation. *AMA Journal of Ethics* 18 (5): 506–513.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.