# Moral Case Deliberation in the face of tragedy

Benita Spronk

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# MORAL CASE DELIBERATION IN THE FACE OF TRAGEDY

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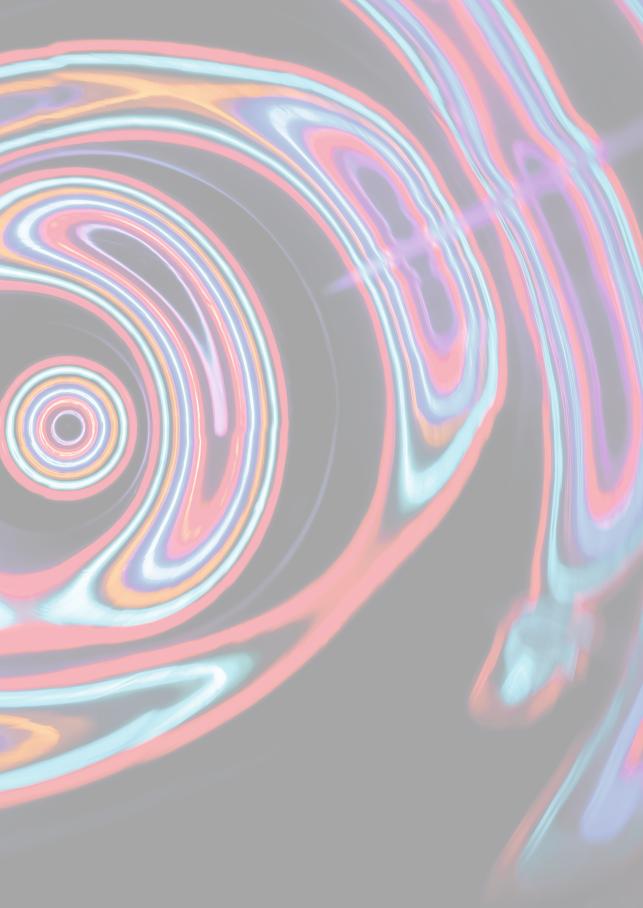
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# **1. General introduction**

# Introduction

When attending moral case deliberations in a hospital department, I became particularly interested in participants' experiences of tragic events. One case concerned a baby on the neonatal ward. This child had already undergone several operations. He had been born prematurely with gastroschisis. His stomach was open and his intestines exposed. Prior to the moral case deliberation (MCD) session, the nurse who had proposed the case took the facilitator to the ward to see the baby in person. During the initial presentation of the case, both nurses and doctors were visibly affected by the situation. Even with all their experience in dealing with seriously ill premature babies, they felt a clear emotional impact. Although this was briefly touched upon during the session, the discussion quickly turned to moral considerations. The parents wanted everything possible to be done for their child. The dilemma centred around the question of whether to take heroic measures, which might well entail yet another operation, or to adopt a more conservative strategy limited to pain mitigation with no further surgical interventions.

The case was presented to participants and the medical background briefly described. The underlying norms and values of those involved were formulated and discussed. The desire to protect the child's life was mentioned, as were the worldview and cultural values of the parents. While these values would support a decision to continuate treatment, also values which would motivate stopping treatment were identified, including the 'do no harm' principle, responsible care providership and the avoidance of medically futile interventions. For the time being, the decision was made to continue maximum treatment in order to give the child one last chance. Dialogue with the parents would be maintained to ensure that they were fully aware of the seriousness of the situation.

For me, this situation brought home the notion of tragedy. It involved a young child having to undergo many operations. It involved parents who had been looking forward to the arrival of their baby but whose anticipation had been cut short by his very premature birth. They could do nothing but watch helplessly as their child was taken time and again to the operating theatre, suffered pain and fought for his young life. The doctors and nurses did everything they could but had reached the limits of what was medically possible. At the end of the MCD session, my impression was that, although a decision was made, the care providers had not reached resolution. I asked myself whether the element of tragedy had been discussed as fully as it might. Had there been enough opportunity to discuss the pain of all the parties involved, or to determine exactly why this situation was so emotionally charged? This made me think: how can MCD help when we are faced with tragic situations in healthcare? What is needed if MCD is to help in situations that involve making extremely difficult decisions? My research focuses on MCD in this type of tragic situation, examining how it can support healthcare staff in making appropriate choices and learning to deal with the situation.

There is some literature about MCD in tragic situations. Delany et al. (2021) report that clinicians are exposed to "human tragedies and stressful events involving conflict, misunderstanding, and moral distress" (p. 573). They emphasize that it is not good to bear the weight of these stressful events alone. They discuss several reflective conversation methods (Psychological First Aid, Critical Incident Stress Debrief, Clinical Ethics De-brief, Clinical Supervision) and point out the need for a facilitator to guide the conversation. Berghmans and De Wert (2004) specifically mention the importance of MCD in tragic situations. They discuss a case of a patient with Parkinson's disease, who was treated with electrostimulation, which affected his mental competence. They describe this case as "a tragic dilemma: a conflict between irreconcilable duties for the physician" (p. 1374). It is not possible to make an unequivocally good choice, because the physician cannot do justice to the appeal arising from the various obligations. This shows that in tragic situations healthcare professionals cannot prevent doing harm, and indicates that MCD can assist them in coming to terms with that. Literature on MCD also shows the importance of dealing with emotions in morally difficult situations (Metselaar et al., 2020; Molewijk et al., 2011 a; Molewijk et al., 2011b). MCD can contribute to mutual emotional support (Metselaar et al., 2020; Molewijk et al., 2011 a; Molewijk et al., 2011b). Emotions can show which values are under pressure (Metselaar et al., 2020). Further attention is needed on how knowledge derived from emotions can be used for moral decisions (Svantesson et al., 2018). In tragic situations, when life is vulnerable due to illness, the meaning of life is under pressure (Monette & Quintin, 2018), and life questions arise (Liao & Chan, 2016). This raises the question how healthcare providers should act in these situations (Monette & Quintin, 2018). Carnavale (2007) argues that in a tragic dilemma, which is a situation that one cannot get out of without 'dirty hands', ethics should focus not on rational decisionmaking, but on how to give meaning to life.

This short overview of the literature makes clear that tragic situations are difficult for healthcare professionals to handle. First, in tragic situations healthcare professionals cannot prevent doing harm and making dirty hands. Second, tragic situations involve emotions, not only of patients and family, but also of healthcare providers. Third, in tragic situations, the meaning of life is at stake. In the literature, it is argued that MCD can support health care providers in these issues, but several questions remain unanswered. How can healthcare professionals discuss tragedy in such a way that they can deal with it? If tragedy has to do with 'dirty hands', with lasting suffering and the insolvability of a tragic situation, how can MCD support healthcare professionals in finding ways to deal with this? How can MCD address emotions related to situations of tragedy? How can MCD assist healthcare professionals in reflecting on issues related to the meaning of life, which is under pressure in tragic situations? When it comes to the importance of tragic situations and what it takes to deal with them, Martha Nussbaum imposes herself as a leading author, who profoundly studied the phenomenon of tragedy. Her book 'The Fragility of Goodness' (2001a, originally 1989) is seen as a standard work on tragedy, in which she examines the fundamental ethical problem that many of the valued constituents of a well-lived life are vulnerable to factors outside a person's control. Nussbaum recovers a central dimension of Greek thought and addresses major issues in contemporary ethical theory. In her work, Nussbaum also addresses the three topics mentioned above. She defines tragedy as a situation in which a person causes harm by having to make a choice between two alternatives which both entail a moral obligation. She also stresses the importance of acknowledging emotions, since they provide an indication of what is truly important to those experiencing them. Finally, she argues that responding to a tragic situation demands reflection on what really matters in life and what one stands for, determining what constitutes 'the good life' and how that can be achieved.

In this thesis, I will examine how insights gained from Nussbaum's philosophical anthropology, and in particular the concepts of harm, emotion and worldview, can shed light on the experience of tragedy in healthcare and the ways in which MCD can assist in dealing with tragedy. A qualitative methodology has been applied. On the one hand, I analyse the experiences of MCD participants with regard to tragedy, while on the other hand I attempt to identify patterns within the experiences of the facilitators who lead the MCD discussions, focusing on the concepts of harm, emotion and worldview.

The next section provides background information on MCD in healthcare. This is followed by an account of Nussbaum's theory of tragedy, including the concepts of harm, emotion and worldview. Next, the aim of the current study, and the research questions are formulated, and the methodology is described. The chapter concludes with an overview of the thesis.

## Moral case deliberation

MCD has emerged as an important instrument which offers healthcare professionals support in answering the ethical questions they face in their day-to-day practice. That practice requires choices to be made, often with far-reaching consequences. Many choices involve a dilemma, which implies that there are two option which both entail some degree of harm. For healthcare professionals, it is important to reflect on the situation and to examine it carefully using a structured approach.

MCD is an eminently suitable method for examining a morally troublesome situation encountered during actual practice. "An MCD is an interactive session in which health care professionals systematically reflect on the moral question(s) that has emerged in concrete personal experience (i.e. a case)" (Stolper et al., 2010, p. 151). The value of MCD is based on the discussion of, and reflection on, a moral issue that a healthcare professional has actually experienced at first hand. Each case is presented by someone who is directly involved. MCD can be either prospective or retrospective. The focus on practice and the direct involvement of participants in the case help to shed light on the moral question at stake. The approach differs from an approach which allows participants to distance themselves and remain dispassionate. In most cases, MCD is conducted within a hospital department and involves participants of various professional backgrounds. The session is led by a specially trained facilitator, who fosters a feeling of safety and promotes open discussion. The facilitator does not offer advice, but guides and supports participants as they examine the underlying moral questions and considerations (Stolper et al., 2010, p. 33). Various methods can be applied such as the Dilemma method and the Socratic Dialogue (Van Dartel & Molewijk, 2014). For this thesis, the Dilemma method is specifically relevant, since it focuses on the tensions between various possible courses of action, and explicitly addresses the harm involved in making a choice. Therefore, the background of this method will be described in more detail below.

In the Dilemma method, the moral question is formulated as a dilemma and discussed as such. The analysis of the case focuses on various aspects, including the norms and values at play (Molewijk & Ahlzen, 2011; Stolper et al., 2016). Values indicate what is seen as important within the case in question. Values underpin the views and proposed actions of the participants. Norms determine the actions which are seen as appropriate, thus concretizing the values in practice. MCD encourages participants to explicate and share their implicit orientations and rules. The various perspectives that emerge enrich the discussion by revealing a range of different views of the dilemma under consideration. The Dilemma method is based on a combination of hermeneutic and dialogic ethics (Molewijk et al., 2008; Widdershoven et al., 2009; Widdershoven & Metselaar, 2012; Widdershoven & Molewijk, 2010; Rudnick, 2007). Specific to the hermeneutic method is starting with actual experiences in practice (Stolper et al., 2010). "Hermeneutic ethics regards experience as the concrete source of moral wisdom. In order to gain a good understanding of moral issues, concrete detailed experiences and perspectives need to be exchanged" (Widdershoven et al., 2009, p. 236). These concrete experiences are essential. They are needed in order to learn and gain new knowledge (Widdershoven et al. 2009; Widdershoven & Molewijk, 2010). In healthcare practice, moral problems are complex and concrete (Leder, 1994). This applies equally to the tragic situations with which this research is concerned. When applying a pragmatic hermeneutic approach, it is important to consider the historical and contextual background of the situations concerned. The approach does not lend itself to generalized interpretations, but requires us to unravel the complex interplay of historical and contextual backgrounds. Pragmatic hermeneutics therefore invites MCD participants to avoid interpreting the situation according to a fixed set of principles, but rather to remain flexible and open to new possibilities (Molewijk et al., 2008).

Specific to dialogic ethics is joint moral deliberation. If we are to examine how MCD supports healthcare professionals in tragic situations, we have to look at the manner in which the deliberation unfolds and the issues which are (or can be) discussed. From a dialogical perspective, MCD implies critically examining one's own viewpoints, and those of others, by means of open conversation. This demands an open attitude on the part of

all participants, avoiding clinging to preconceived ideas and allowing norms and values to be discussed by the group as a whole. "Dialogical understanding means that one tries to see the point the other makes" (Molewijk et al., 2008, p. 121; see Gadamer, 1960).

This thesis focuses on actual experiences of MCD participants and facilitators when confronted with a tragic situation. We first examine how a tragic situation is discussed and how the tragic element is experienced in a concrete example of an MCD. In this MCD, the Dilemma method was used. We further examine what can be expected of MCD in a tragic situation, and the demands placed upon facilitators if they are to ensure that the deliberation is as effective and productive as possible. For this purpose, we interviewed facilitators of MCD. We included facilitators who use the Dilemma method, but also facilitators who apply other methods, in order to have a broad range of views and experiences. Discussing tragic situations in MCD is a challenge for any facilitator. Because that was our primary focus, we did not focus on differences in approach and experience related to the methods facilitators use.

#### Nussbaum's work on tragedy

This research draws upon Nussbaum's philosophical anthropology, in which the concept of tragedy plays a key role. This section offers a brief description of Nussbaum's ideas about tragedy, elaborating on the importance of the concepts of harm, emotion and worldview. In line with the literature about MCD in tragic situations, discussed above, these three concepts were chosen in advance as we expected them to be relevant for the investigation of the potential support of MCD in tragic situations. By examining Nussbaum's elaboration of these concepts, we can get more insight in the philosophical aspects involved. This can help to examine the views and experiences of participants in practice, both healthcare professionals and facilitators of MCD, as it can inform the questions raised in the interviews and provide a focus in the analysis of the interviews. In this way, theoretical notions can be used as sensitizing concepts, providing a point of entrance, but remaining open to change, based on the empirical findings (Charmaz, 2006). Charmaz describes sensitizing concepts as "those background ideas that inform the overall research problem. Sensitizing concepts offer ways of seeing, organizing, and understanding experience" (2003, p. 259).

Nussbaum draws a distinction between tragedy that befalls us by chance, such as illness or an accident, and tragedy which is not the result of external forces but is something for which we are ourselves responsible, the result of choices we have made as a 'moral agent'. Tragedy in the former sense is related to the fragility and unpredictability of life (Nussbaum, 2001a, p. 399). This is something with which healthcare professionals are confronted on a daily basis as they care for patients who are sick or have suffered an accident. As difficult and painful as it may be, it is a fact of life. For Nussbaum, the real challenge lies in the tragedy which results from our own choices. Healthcare providers can be responsible for tragedy in this sense, as they have to make these choices. In the dilemmas they face, they cannot escape making choices, even if they would prefer to do so. Every dilemma that is the subject of MCD involves care providers who cannot avoid violating the values that they hold dear. Nussbaum terms this a 'tragic conflict'.

In such cases we see a wrong action committed without any direct physical compulsion and in full knowledge of its nature, by a person whose ethical character or commitments would otherwise dispose him to reject the act. The constraint comes from the presence of circumstances that prevent the adequate fulfilment of two valid ethical claims. Tragedy tends, on the whole, to take such situations very seriously. It treats them as real cases of wrong-doing that are of relevance for an assessment of the agent's ethical life. (Nussbaum, 2001a, p. 25)

As an example, Nussbaum cites the plot of Aeschylus' play Agamemnon, in which the title character is forced to sacrifice his own daughter in order to save the expedition he is leading. He has to make a choice, and is overwhelmed by the impact of his decision. "He acknowledges that there is wrong done whichever way he chooses" (Nussbaum, 2001a, p. 35). It was the gods who brought him into this situation, and there is no way out without causing harm (p. 34). However, Agamemnon believes that there is a 'right' course of action representing the lesser of two evils (p. 36). He fails to acknowledge the harm that this will cause. The chorus berates Agamemnon for not having foreseen the gravity of his actions (p. 35). He assumes that those actions could be termed 'good', because he had made the better choice under the circumstances. In his view, the conflict he faced has been resolved. "Agamemnon's conclusion, which from one point of view seems logical and even rational, omits the sorrow and the struggle, leaving only the good"(Nussbaum, 2001a, p. 36). Nussbaum states that we must acknowledge that there will always be lasting harm on both sides of the dilemma. In the case of tragedy, ongoing awareness of the sorrow and the struggle is of eminent importance.

Elsewhere Nussbaum distinguishes between situations in which a course of action can be chosen on the basis of a cost-benefit analysis ('the obvious question'), and those in which this particular model cannot be applied because they involve the care provider giving something up ('the tragic question')(2000a, pp. 1005-1036). This type of dilemma has two opposing alternatives, both of which result in loss and are morally unacceptable (Molewijk et al., 2008; Nussbaum, 2001a, p. 27; Stolper et al., 2016). A cost-benefit analysis is therefore futile. The question goes beyond merely finding the best possible course of action: it demands awareness of the limitations of each consideration, and the realization that weighing the options one against the other will not determine what constitutes the good life (Manschot, 2003, p. 237).

From the above we can conclude that, according to Nussbaum, in a situation of tragedy, harm cannot be avoided. The decision will always be difficult because all options bring

some moral cost. Sometimes, the better choice will be obvious but there will still be harm in the form of pain, sorrow or frustration caused by the inability to safeguard other interests. The situation will continue to be felt as a conflict, even though the decision itself is obvious. Nussbaum gives the example of a ship's captain who is forced to jettison a valuable cargo in a storm. It is clear what has to be done: if he keeps the cargo, the entire ship will be lost. Nevertheless the sense of loss remains (2001a, p. 27). Nussbaum states that it is sometimes possible to place one alternative above another. "Sometimes one choice may be clearly better than another in a tragic situation, even though all available choices involve a violation of some sort" (2011, p. 37). Even where one choice is clearly better than another, this does not alter the fact that tragedy goes hand in hand with harm.

Next to elaborating the notion of harm in relation to tragedy, Nussbaum provides insight in the relevance of emotions in tragic situations. Since a care provider in a tragic situation is unable to prevent harm, this will evoke negative emotions, as care providers have to live with a sense of loss. Nussbaum subscribes to the Aristotelian theory of emotion, which holds that emotions are not solely a negative force. Emotions actually have a positive function because they are derived from, and thus an indicator, of what people find truly important. This applies to all emotions that we experience as human beings. Two emotions play a particularly prominent role in tragic situations: 'pity' and 'fear' (Nussbaum, 2001a, p. 383). Both have a clear connection with 'harm'. Pity is concerned with the pain or suffering of someone else. Care providers work to prevent or mitigate their patients' pain or suffering. Pity shows that not only the care receiver is vulnerable, but also the care provider. This emotion goes hand in hand with the thought that "luck is seriously powerful, that it is possible for a good person to suffer serious and undeserved harm, that this possibility extends to human beings generally" (p. 385). "Fear is defined as a painful emotion connected with the expectation of future harm or pain" (p. 385). Care providers do whatever they can in caring for their patients. Fear of how to act in the right way in order to prevent causing harm to their patients might play a part if they feel responsible for their patients in tragic situations. They are keen not to cause harm but know that, in a tragic situation, it is not possible to preclude harm. The function of the Greek tragedy is to depict these emotions, thus providing a "clarification or illumination concerning experiences of a pitiable and fearful kind" (p. 391).

In her later work, Nussbaum examines emotions in more depth. "Emotions [...] involve judgments about important things, judgments in which, appraising an external object as salient for our own well-being, we acknowledge our own neediness and incompleteness before parts of the world that we do not fully control" (Nussbaum, 2001b, p. 19). This is in line with "the ancient Greek Stoic view, according to which emotions are forms of evaluative judgment that ascribe to certain things and persons outside a person's own control great importance for the person's own flourishing" (p. 22). Emotions stem from intelligence and are allied with the human ability to differentiate. This is why they cannot

be ignored (pp. 19-88) and confirms that emotions are important in tragic situations, since they help to reveal important values.

Nussbaum shows that tragedy, alongside harm and emotions, is linked with the way in which care providers view life, i.e. their worldview. "Worldview refers to fundamental beliefs about life, death and suffering that structure people's ideas on how life events are related" (Littooij et al., 2016, p. 7). It involves guestions that touch upon the fundamentals of our existence, determining who we are and where we wish to belong (Aerts et al., 2007. p. 5: Alma, 2018. p. 45: Plante & McCreadie, 2019. p. 321: Tayes et al., 2018). Worldview offers a view of what is truly valued in life and what can help one cope with tragic situations. In her elaboration of the Capabilities Approach, Nussbaum refers to the importance of wordview. "Being able to search for the ultimate meaning in life in one's own way" (2000b, p. 79), is a human capability that must be supported. Our fundamental moral values are connected to our worldview (Nussbaum, 1998, p. 52, 53, 128). According to Nussbaum, emotions, values and worldview are related. Our emotions express our worldview. "(..) the things that occasion a strong emotion in us are things that correspond to what we have invested with importance in our thoughts, implicit or explicit, about what is important in life, our conception of flourishing" (2015, p. 145). For every educated citizen, Nussbaum says, learning facts and mastering techniques of reasoning are important. "But it means something more. It means learning how to be a human being capable of love and imagination" (Nussbaum, 1998, p.14). By attaching importance to such values, we make ourselves susceptible to potential threats. Nussbaum believes that it is important not to focus on controlling life experiences but to remain open and receptive to reality. a concept she terms 'exposure' (2001a, pp. 18–21), which she describes as an essential component of the ability to lead a good life. Smart (1992) proposes seven dimensions of worldview: philosophical or doctrinal (beliefs), ethical, experiential, material, social, mythic and ritual. Nussbaum is primarily concerned with the ethical dimension and less with the underlying philosophical or doctrinal dimensions (the substantive components of religion or worldview). Our research also focuses on this ethical dimension and the connection of worldview with the practice and experience of care providers. Expressing our worldview might help us to deal with tragic situations or give them a place in our lives.

In summary, care providers can be called upon to make decisions in dilemmas in situations that can be described as tragic. Those choices inevitably involve harm. Also, emotions play a role in tragic situations. Finally, moral values which are bound up with the worldview of care providers are relevant. How can MCD provide support to care providers, and help them in dealing with issues concerning harm, emotions and worldview, which are prominent in tragic situations?

1

# **Objective and research questions**

#### Objective

The object of our research is the potential contribution of MCD to dealing with tragic situations in the healthcare setting. MCD is one of a range of interventions that can support care providers who are required to make moral choices. It aims to ensure that they approach the situation in a responsible manner, and that they are able to stand behind their decisions, in relation to whatever effects the case and the subsequent decision have on all the people involved.

The objective of this study is to clarify how MCD can provide support to healthcare professionals in tragic situations. What is needed if MCD is to help in situations which require a care provider to make a choice which will inevitably result in moral damage, entail emotions and touch upon the meaning of life? What are the implications for facilitators? This study is therefore intended to clarify how MCD can help care providers to make moral choices in particularly difficult circumstances. Reflection on what is needed in making difficult choices can contribute to the ability to provide good care.

#### **Research questions**

The main research question is: How can healthcare professionals be supported in dealing with tragic situations through MCD?

This gives rise to two sub-questions:

- 1. How do MCD participants experience the support provided by MCD in dealing with a tragic situation?
- 2. How can facilitators support healthcare professionals in tragic situations, and assist them in dealing with issues related to harm, emotion and worldview?

The first step is to get to know the field with which we are concerned. This is the focus of the first sub-question: What do MCD participants say about the way in which MCD supports them in dealing with a tragic situation? What do they understand by tragedy, and how does MCD support them in the specific case which requires decisions to be made?

The second sub-question examines the contribution made by MCD facilitators. The three themes drawn from Nussbaum – harm, emotion and worldview – inspired me to investigate facilitators' views on MCD in tragic situations more in-depth. How do MCD facilitators address the three themes in guiding the participants through the process of reflection? How do they assist participants in dealing with issues related to harm, emotion and worldview??

#### Methodology

To answer the first sub-question, we conducted interviews with the participants in an MCD concerning a case which certainly qualifies as 'tragic'. We examined how the participants experienced the tragedy, and how supported they felt after the MCD. Semi-structured interviews were held with ten healthcare professionals who were involved in the patient's treatment, and had attended three MCD sessions at which the case had been discussed (N=10). The interview results were analysed using qualitative methods, focusing on the views and experiences of the interviewees (Patton, 1990). This set of interviews was used for the first article presented in this thesis.

To answer the second sub-question, we conducted interviews with twelve trained MCD facilitators (N=12). Given their practical experience, facilitators are a prime source of knowledge about the mechanisms and effects of MCD. The interviewees were asked to give examples of MCD sessions that they had led, in which tragic situations were discussed. Also, they were questioned about their views and experiences in MCD with regard to tragedy, harm, emotion and worldview, which served as sensitizing concepts. This set of interviews was used for the other articles in this thesis. For each article, a separate analysis was performed, based on a different research question. This part of the study relied on the Grounded Theory approach, as developed by Charmaz (2006). This method entails collecting and collating data by inviting respondents to describe and present their own viewpoints and experiences, whereupon the resultant information is subject to further analysis on the basis of sensitizing concepts. The sensitizing concepts applied in this study are harm, emotion and worldview. Research focused on how these three aspects of tragedy are addressed in MCD, and how facilitators can support professionals in dealing with them in healthcare practice.

#### **Overview of the thesis**

The main body of the thesis comprises four chapters, originally written as separate articles. Chapter 2 presents an MCD concerning a tragic case. How did the participants experience the situation of tragedy? What support did MCD provide? Here, the focus is on the views and experiences of the participants, based on sub-question 1. In Chapter 3 we examine the significance of addressing harm as part of the MCD process, as experienced by the facilitators (first theme of sub-question 2). Chapter 4 is concerned with the significance of addressing emotion, again from the perspective of the facilitators (second theme of sub-question 2). In Chapter 5, we turn to the significance of worldview within the MCD process, as reported by facilitators (third theme of sub-question 2). In Chapter 6 we answer the research questions and place our findings in a broader perspective. There we return to the relevance of our findings regarding the support that MCD can provide to care professionals in tragic situations, and to the implications for the practice of MCD.

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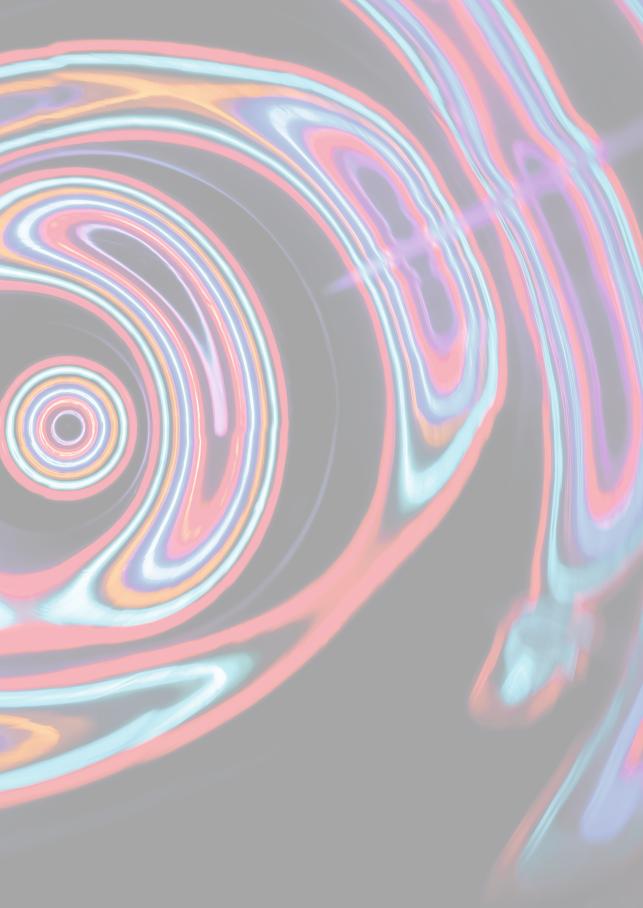
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General introduction



# 2. Tragedy in moral case deliberation

**Keywords:** Tragedy | Moral case deliberation | MCD | Decision-making | Dilemma method | Contingency

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# Abstract

In healthcare practice, care providers are con-fronted with tragic situations, in which they are expected to make choices and decisions that can have far-reaching consequences. This article investigates the role of moral case deliberation (MCD) in dealing with tragic situations. It focuses on experiences of care givers involved in the treatment of a pregnant woman with a brain tumour, and their evaluation of a series of MCD meetings in which the dilemmas around care were discussed. The study was gualitative, focusing on the views and experiences of the participants. A case study design is used by conducting semi-structured interviews (N = 10) with health care professionals who both played a role in the treatment of the patient and attended the MCD. The results show that MCD helps people to deal with tragic situations. An important element of MCD in this respect is making explicit the dilemma and the damage, demonstrating that there is no simple solution. MCD prompts participants to formulate and share personal experiences with one another and thus helps to create a shared perception of the situation as tragic. The article concludes that MCD contributes to the sharing of tragic experiences, and fosters mutual interaction during a tragedy. Its value could be increased through explicit reflection on the aspect of contingency that characterises tragedy.

## Introduction

In professional practice, care providers are confronted with tragic situations, in which they are expected to make choices and decisions that can have far-reaching consequences. The dilemmas faced by practitioners are often urgent, requiring immediate decision-making. Frequently the choice to be made is not between good and evil, but between a greater and a lesser evil. Should a practitioner proceed with an operation that will extend the patient's life by only a few weeks? Or is it preferable to withhold treatment, to ensure better quality of life? Should artificial respiration be given to a severely disabled infant with bleak prospects, or should the focus be on keeping the child comfortable and reducing suffering? The choice is between two evils, and searching for the best treatment option.<sup>1</sup> Although care providers must make decisions regarding what medical action to take, this does nothing to lessen the tragedy of the situations they face. Every option has an inevitable moral downside.

To support care providers in making these choices, many Dutch hospitals offer 'ethics support'. Research by Dauwerse et al. (2011, p. 84) has shown that 81 per cent of Dutch healthcare institutions acknowledge the necessity of clinical ethics support, stating its purpose as 'promoting decisions with an ethical dimension'. Moral case deliberation is one of the instruments used as part of clinical ethics support (Dauwerse, 2014). During moral case deliberation, healthcare professionals use a concrete case to explore what is at stake in a moral dilemma, and to identify the associated key (and possibly conflicting) values.

This article discusses an instance of moral case deliberation in a case that the participants clearly identified as tragic. Tragedy has many forms. On the one hand there is the tragedy as experienced by the patient. The case in question involved a pregnant woman with a brain tumour. She suffered severe from her illness and stood before the choice of keeping hope or accepting the end. On the other hand there is the tragedy as experienced by the care providers standing at her side, supporting her in the choices she had to make, feeling responsible for the decisions they had to take. This article focusses on tragic as experienced by care providers. Interviews were conducted with those involved to determine what it was that made the situation tragic for them, and how the inherent tragedy was dis- cussed during the deliberations. The central question addressed by this study is: What is the role of moral case deliberation in dealing with tragic situations?

We will begin by defining the concept of tragedy based on literature. This is followed by an introduction of moral case deliberation as an instrument to support healthcare professionals in dealing with ethical issues. After that, we will describe the research method used. Next the results of the study are presented, ordered according to three

<sup>1</sup> Recent research that discusses the gravity of forced decision-making: 'Sharing the burden of deciding: How physicians and parents make end-of-life decisions' (De Vos-Broerse, 2015).

sub- questions: What characterises this case as tragic? How does moral case deliberation bring this tragedy into focus? What do people need in tragic situations? The discussion analyses the findings, and concludes that moral case deliberation contributes to the sharing of tragic experiences, and aids mutual interaction during a tragedy. Its value could be increased through explicit reflection on the aspect of contingency that characterizes tragedy.

## The concept of tragedy

People cannot control life. Things will always happen that we are powerless to change. This idea is given profound expression in the Greek tragedies, which examine the attempts made by people to come to terms with the things that happen to them: with undeserved setbacks, violence or the irrevocable nature of events (Manschot, 2003, p. 226). Tragedy also relates to the vulnerability of life (Nussbaum, 2001a, p. 399), and if there is any place where life's vulnerability is patently evident, it is a hospital. Patients are confronted with the vulnerability of their own bodies, and—through their patients—practitioners encounter vulnerability in the form of the realisation that not all illnesses can be cured. As autonomous agents, this hard to bear. We would rather be immune to setbacks (Sloterdijk, 2004, pp. 192 v, 249, 534). But where the real challenge lies, according to Nussbaum, is in tragic conflict.

In such cases we see a wrong action committed without any direct physical compulsion and in full knowledge of its nature, by a person whose ethical character or commitments would otherwise dispose him to reject the act. The constraint comes from the presence of circumstances that prevent the adequate fulfilment of two valid ethical claims. Tragedy tends, on the whole, to take such situations very seriously. It treats them as real cases of wrong-doing that are of relevance for an assessment of the agent's ethical life. (Nussbaum, 2001a, p. 25).

As an example Nussbaum cites Agamemnon, who must sacrifice his daughter in order to save the expedition he is leading. He must choose, and is consumed by the impact of the decision he is to make. "He acknowledges that there is wrong done whichever way he chooses" (p. 35). The gods have put him in this situation, and there is no blameless escape (p. 34). Nevertheless, Agamemnon still sees it as his own decision for which he himself bears responsibility (p. 35).<sup>2</sup>

<sup>2</sup> In tragic cases, Fredriksen speaks not in terms of guilt, but in terms of responsibility. 'Professionals do not have to accept responsibility in the sense of culpability—in the sense that they misjudged the situation and should have acted differently. But they must accept responsibility(-)' (Fredriksen, 2006, p. 452).

In another article, Nussbaum draws a distinction between situations in which one must decide on a course of action ('the obvious question') and where a cost-benefit analysis can be applied, and situations involving the question of what one must give up ('the tragic question')(2000, pp.1005-1036). The latter case involves a dilemma—two alternatives that both result in a loss and are morally objectionable (Molewijk et al., 2008; Stolper et al., 2016). A cost-benefit analysis is of no use in such cases. The question is more than a mere study of how to best consider the available courses of action—it concerns the limitations of such considerations, and the understanding that weighing up options does not help one to decide what constitutes a good life (Manschot, 2003, p. 237).

This article is based on Nussbaum's definition of tragic conflict. A tragic situation is one in which one is forced to make a choice that will inevitably be accompanied by moral objections. Tragedy and dilemma go hand in hand. Healthcare professionals play a role as actors in the tragic dilemma. This highlights the importance of tragic casuistry and demonstrates that for healthcare professionals, there is much at stake.

Confrontations with tragedy are not necessarily always negative experiences. Life is also enriched by the fact that we can be touched by others, and by what we experience. Friendship and love may bring vulnerability to life, but they are also precisely what give it value. By holding these values high, we also render ourselves vulnerable to potential threats. Although it may be our deepest wish to control or resolve tragedy, it is important to realise the futility of this attitude and to open ourselves up to reality as it is. Nussbaum refers to this process as 'exposure' (Nussbaum, 2001a, pp. 18–21), which she sees as an essential component for leading an ethical life.

#### Moral case deliberation

Moral case deliberation (MCD) is form of clinical ethics support (Dauwerse, 2014; Molewijk et al., 2008; Stolper et al., 2010; Weidema et al., 2013) that has become increasingly popular over the last 15 years. The aim of clinical ethics support is to assist care providers in ethical matters that they encounter in practice. Instead of providing expert advice, new forms of clinical ethics support (such as MCD) aim to provide opportunities that foster moral reflection (Dauwerse, 2014, p. 10). MCD is a structured and methodical dialogue led by a facilitator, in which health care professionals explore a moral issue from a concrete situation in their own realm of experience. The case is brought in by a participant, who was (or is) directly involved themselves. MCD seeks to explore both the factual situation as well as the perceptions and moral perspectives of both the person contributing the case and the other participants.

The purpose of MCD is to have the participants reflect critically on healthcare practice and their associated normative presuppositions, and to improve them wherever possible and desirable. Participants explore their personal moral considerations and share them with one other in the spirit of equality (Weidema et al., 2013, p. 619). This exchange of experiences facilitates greater mutual understanding and a broadening of perspectives. The primary objective of MCD is not to find a solution to the issue, but rather a 'fusion of horizons' among the participants (Gadamer, 1960).

The facilitator gives structure and depth to the dialogue by means of a conversation method. This provides perspectives on how to act and thus makes a difference for decisions in medical care. The MCD meetings in which the present case was discussed used the dilemma method (Molewijk & Ahlzen, 2011; Stolper et al., 2016). The dilemma method consist of ten steps: 1. Introduction, 2. Presentation of the case, 3.Formulating the moral question and the dilemma, 4. Clarification in order to place oneself in the situation of the case presenter, 5. Analysing the case in terms of perspectives, values and norms, 6. Looking for alternatives, 7. Making an individual choice and making explicit one's considerations, 8. Dialogical inquiry, 9. Conclusion, 10. Evaluation (Stolper et al., 2016). This method focuses on the dilemma faced by the case contributor, which is described in terms of two mutually exclusive treatment options.<sup>3</sup> A key feature of the dilemma method is attention to the adverse effects caused by each of the treatment options. This makes it directly compatible with Nussbaum's concept of tragedy discussed above, which involves two valid ethical claims that cannot both be fulfilled.

# Method

The method used is that of a case study (Yin, 2014): a meticulous, in-depth and detailed examination of a series of MCD meetings relating to a tragic situation. The present case concerns not only the patient case that was discussed during the MCDs, but also—and perhaps most importantly—the reflection on the patient case during the MCD meetings. It is an empirical study of what participants understand by tragedy, based on interviews. The case is analysed with qualitative methods, focusing on the views and experiences of the participants (Patton, 1990).

#### Data collection

In this study, semi-structured interviews were used to interview health care professionals who were both involved in the case and attended the MCD meetings when the case was discussed (N = 10). Twelve of the parties involved were approached for an interview. Of these twelve, one person proved to have had only incidental involvement with the patient and the MCDs, and another had already left the organisation for position elsewhere. A total of eight medical specialists from various fields (a gynaecologist, a gynaecologist/perinatologist, a neurologist/sonographer, a neonatologist, a GP and a midwife.

<sup>3</sup> As opposed to the Socratic Dialogue, which uses a conceptual question as a starting point (Kessels et al., 2006, 2009).

The interviewees were asked about what made the case a tragic one in their eyes, and about the role played by MCD in bringing this into relief. The questions asked during the interviews were based on literature studies, participant observation by the researcher during MCDs, and general background discussions with medical ethicists and hospital professionals with MCD experience. All interviews were recorded (with the respondents' permission), transcribed and anonymised. No ethics approval was required for the study, as no patient treatments were being imposed.

#### Analysis

Respondents were given the opportunity to review the text, and revise it where necessary. The interviews were analysed by hand (manual coding) (Saldaña 2013). The transcripts were read and examined sentence by sentence, in search of similarities and differences (initial coding), with sentences being summarised as single words or brief sentences (descriptive coding). Attention was also devoted to any salient words (in vivo coding) or contradictions (vs. coding) apparent in the text. Furthermore, the reflections of the individual researcher(s) during both the interviews and the coding process were noted down (analytic memos). These notes helped to establish links and reveal noteworthy patterns throughout the interviews. All of the codes were subsequently analysed and summarised according to topic (thematic analysis). To guarantee quality, coding was performed by multiple researchers who also acted as peer debriefers throughout the study, and discussion partners for both the design of the study and the results and topics.

#### Selection of the case and the associated MCD meetings

The following criteria were applied when searching for a suitable case:

- In view of the research question, the case discussed during the MCDs must include a strong element of tragedy, commensurate with the definition of tragedy given above;
- At least one MCD meeting must have been held regarding the case;
- The parties involved in the case must be traceable and have taken part in the MCD meetings;
- The case and MCD meetings must not have taken place more than one year ago, to ensure that the parties involved can still readily call their experiences and memories to mind.

#### The case and the moral case deliberations

The case involves a 38-year old female patient. She has several children. The department's annual report describes the case as follows: 'Ten weeks into her pregnancy, the patient was admitted to the neurology department elsewhere due to suspected Cerebro Vasculair Accident (CVA) suggested by loss of strength on the right and subsequent seizures. A Computer Tomogram (CT)-scan revealed a leftfrontal space-occupying lesion. Four weeks later she was referred to a University Hospital, and in the meantime started suffering aphasia and facial paralysis.

The Magnetic Resonanse Imaging (MRI) revealed a progressively growing lesion, and the decision was made to take a brain biopsy. Histopathology revealed an infection consistent with vasculitis. The possibility of a tumour could not be excluded. Following crossdisciplinary consultation, a short course of methylprednisolone was administered to reduce brain oedema and thus relieve symptoms. During the 16<sup>th</sup> week of pregnancy, a craniotomy was performed to relieve intracranial pressure under a diagnosis of vasculitis. A left-frontal section of bone was removed and an open biopsy taken, which revealed a glioblastoma localised in the leptomeningeal space. Due to the extensiveness, character and multifocality of the tumour, the possibility of further treatment was excluded. The pregnancy had no influence on the prognosis. Despite her aphasia, the patient expressed a clear wish to continue with the pregnancy. Her husband supported this decision.

From the 17th week onwards, the woman was cared for at home under the direction of the general practitioner/midwife in weekly/daily consultation with the neurologists and gynaecologists.

The 20-week ultrasound gave cause to suspect oesophageal atresia in the foetus. The parents declined invasive diagnostics. Although the patient's clinical condition was deteriorating rapidly, expected time to death remained uncertain since the craniotomy eliminated intracranial pressure as a possible cause.

The first MCD meeting, facilitated by an ethicist, took place during the 20th week of pregnancy. At this time the patient was still mentally competent. A report of the meeting was drawn up, which formulated the dilemma as follows:

(A) We treat the patient (with a feeding tube/antibiotics to improve the child's prospects), or

(B) We give no further treatment except for comfort/palliative care.

'Needless suffering' was formulated as a negative consequence of option A, and poor prospects for the child in the case of option B. Both alternatives have a direct impact on patient care.

An analysis of the norms and values from the perspectives of each of the parties involved is given below. A 'value' represents what is important for a person in the situation at hand, a 'norm' formulates the rule of action needed to realize a specific value (Table 1).

Perspective	Values	Norms
Patient	Trust	I should trust the doctors
	Lots of children	Now that I am dying, I would like to have this child (even with Down Syndrome)
	Healthy baby	If the baby dies, I can care for it in heaven
	Concern for husband	l have to take care of my husband
Husband	Compassion	I must be there for my wife
	Obedience	I should do what she wants
Patient's mother	Right to protection (of the unborn child)	I don't want any discussion
	Willingness to help	My daughter needs help
	Stand up for my daughter	The doctors have to be less clinical
	Distrust	l need to check up on the doctors
Foetus	(No data)	
Neurologists	Patient first	We must not do anything that is not in the patient's interests
Gynaecologists and paediatrician	Maturity of the child	The intervention limits must be raised to increase prospects for the child
	Support of mother and child	A scenario must be developed
Brothers/sisters	(No data)	

Table 1. Analysis of norms and values

Based on the discussion, all participants then considered matters individually and responded to the dilemma formulated above. Each participant also stated which value 'tipped the balance', which ones were left unaffected (by not choosing the alternative), and how the damage could be repaired. The individual choices were tabulated and compared with one another, which led to a dialogue among the participants on the similarities and differences, and what could be learned from the viewpoints of others.

By the end of the meeting there was a broad consensus among the participants regarding the course of action to take: option B, i.e. no further treatment except for comfort/palliative care. This was the option chosen to be suggested to the patient for consent. The underlying reason for this choice was poor likelihood of a healthy child. Further treatments would

be likely to cause even more harm. To limit the damage, it was agreed to communicate the decision clearly due to the importance of trust in the patient-doctor relationship. They decided to include the patient's husband and mother in this process, the patient had given consent to their involvement, and to provide them with extensive support. The situation was so exceptional and tragic that it was decided to deliver the decision (and explanations) during a home visit to the patient and her family. A visit to the hospital would be too much for her.

A second MCD meeting was held during the 27<sup>th</sup> week of pregnancy, led by the same ethicist. A report of this meeting was also drawn up. At the start of the meeting it was announced that the planned home visit did not take place, because the GP had assumed responsibility for communications. The GP was present at this new MCD meeting. The woman's condition had deteriorated: she now has a large swollen mass on her head, and can only move half of her body. She is bedridden, and can consume liquid foods. She can no longer speak; indicating her understanding is sporadically possible, but is becoming less and less so. At this time she had indicated that her mother should be her representative. Her husband was not talkative, and kept himself in the background. The decision against invasive life-prolonging treatment in the interests of the child is still in force. The situation has changed however, as the child now has a chance of survival if it is born. The new question concerns what to do if the patient's condition suddenly worsens, presenting an acute threat to the child. Moral choices concerning medical decisions not only have impact on the patient care of the mother, but also on the life of the child.

The interests of the child are now paramount, and any decisions should aim to give the child the best possible chance of survival and quality of life. Consequently, this would mean delaying the birth for as long as possible. One crucial aspect of the child's prospects is the question of the oesophageal atresia (and the possible complication of Down Syndrome). There are signs that this may be the case. Operating on a child for oesophageal atresia before 32 weeks is difficult, and chances of survival are slim. They decide to perform another ultrasound. This would require the patient to come to the hospital, unless a company can be found that would be willing to provide a portable ultrasound scanner. The sonographers agree to try to organise one.

Now there are two conceivable scenarios. If oesophageal atresia is confirmed, it only makes sense to take action after 32 weeks if there are any complications. Hospital admission for feeding tubes or a C-section is only useful after this point—until then, the policy is to wait. In the absence of oesophageal atresia, the 32-week limit does not apply. The importance of the ultrasound and the two scenarios will need to be thoroughly explained to the family.

If a C-section is required, for example, what should be done if there are any complications (such as haemorrhaging)? Although the woman ultimately has no chance of survival,

denying any form of treatment would seem rather extreme. They decide to treat her normally (e.g. via a blood transfusion), and to avoid invasive procedures such as operations or admission to IC. There is a limit regarding what would be beneficial, given her limited life expectancy and quality of life.

Because the ethical issue had not changed significantly since the first meeting, there was no need to carry out a new analysis in terms of norms and values. The discussion revolved primarily around how to apply the previous normative conclusions in light of the new circumstances (improved prospects for the child). The outcome of the MCD meeting was to continue along the lines established during the first meeting: administer no treatment to prolong the woman's life that could potentially endanger the child. Despite the tragic nature of the situation, this perspective allows a clear line of action to be established that everybody can agree with. Communication with the family remains an important issue.

The department's annual report describes the conclusion of the case as follows:

(-) A home visit was then made by the gynaecologist, midwife and sonographer from the University Hospital to carry out another detailed ultrasound. This screening, at 27
+ 2 weeks, revealed a case of Intra Uterine Foetal Death. The patient died at home that evening. No autopsy was performed.

Some weeks after the patient's death, a third meeting with the ethicist was organised in order to look back on the events and decisions that were made with those involved. This concluding session was freer in character, and no structure was imposed by the ethicist.

The three meetings were attended by a total of twelve healthcare professionals in varying combinations, ten of whom were interviewed. Three of the ten interviewees had prior experience with MCD. The interviews were conducted 1 year after the case and the MCD proceedings.

#### Results

This section seeks to successively answer the three subquestions formulated above. First we will describe five tragic elements in the case according to the respondents, and then discuss five aspects of moral case deliberation that played a role in helping the tragedy to manifest. Lastly, we give the respondents' opinions on what is required during moral case deliberations on tragic situations such as this.

#### What characterises the tragedy in this case?

Respondents were asked what characterised the tragedy in this case. Five elements were found.

The first element that the respondents believed characterised the tragedy was its *impact*. All respondents state that the case stayed with them. Even after a year had passed, they could still easily call the situation to mind without needing to refer to the medical reports. One of the respondents described the repercussions of the case as follows:

There are some cases that just stay with you, and this is one of them (...). The tragedy of a pregnant woman with both a child in situ and a rapidly progressing malignant process... it leaves its mark on you. It gave me sleepless nights, and (...) the problem was we were always dealing with mother and child, we had to consider both. (Interview 5)

A second element was the *intensely sad* nature of the situation. The respondents called it a 'sad' situation for both the mother (who is carrying a child that she will never be able to raise) and for her partner (who will be left with several children). They were also emotionally affected by the situation, and the fact that there were several other children amplified the feeling of sadness:

Yes, absolutely. Of course we were all incredibly consumed by the tragedy of it all. And we... everybody could at least... you know, we could get it off our chest, so to speak. But of course, we all felt, maybe some of us were secretly kind of thinking like, man, the husband, you know. It's all well and good for her to want the child, but her husband already has all those kids to deal with, and then there could be an extra disabled one, with all the extra care required. What on earth is he supposed to do? (Interview 4)

The third tragic element is the *acceptance* of the inevitable. The inevitability of the mother's death was of course openly expressed during the MCD sessions. The respondents were ultimately relieved when mother and child died together, giving them a certain peace of mind:

I'm glad things went the way they did, in the end I'm happy she died with her baby inside her, and that they were buried together. It was just like she wanted, so I am at peace with what happened. (Interview 10)

The fourth tragic element revealed by the interviews was *powerlessness*. The case presented an unexpected turn of life events attributable only to bad luck and misfortune, which made those involved feel powerless.

The word actually says it all, right? (long pause) An insurmountable...(long pause)...something ominous with an... inevitable conclusion. Something that... 'cause it's tragic, of course. (-) And it's irrevocable too, there are no winners. It's the worst thing you can imagine. (-) There's no way around it, you know? It's going to happen... powerlessness'. (Interview 7)

The fifth element of tragedy concerns the threat to *human dignity*. The decision of whether or not to provide treatment will affect how the patient will die, and particularly whether she can do so with dignity:

For me, the complex issue was the huge list of possible scenarios due to the combination of the patient's malignant disease and missing a piece of her skull. (-) And the list only got longer, because all the scenarios we created for the mother also had consequences for the child. So making her feel as comfortable as possible – essentially giving her a... a dignified death in the relatively short term – that of course denies her child the opportunity of being born alive. On the other hand, a barrage of treatments to extend the mother's life would make her situation more and more undignified... [but] would improve prospects for the child. (Interview 9)

#### How did moral case deliberation bring this tragedy into focus?

What role did MCD play in bringing the tragedy of this case to the fore? The interviews revealed five aspects of the role played by moral case deliberation in tragic situations.

The first of these is the fact that MCD *clarifies the dilemma* through the concrete formulation of two treatment options. The dilemma method places the emphasis on conflicting values and interests. The dilemma during the first MCD session was formulated by one of the respondents in the following quote:

During that MCD session (...) the main issue was: what things are important for the mother, and which are important for the child? The real moral component was that any decision to treat the mother and reduce her suffering might do damage to the child. (Interview 6)

Giving comfort to the mother and ceasing treatment means that she will die sooner, but will deny the child the opportunity of being born alive. Conversely, while all treatment to extend the mother's life increases the prospects for the child, they prolong her suffering.

The second MCD session focused on the child. During the 20th week of pregnancy, there was reason to suspect that the child may have had a serious birth defect. Healthy children with enough bodyweight can be born prematurely, as they are more likely to survive. This child's chances were slimmer, however, due to the suspected abnormality. The question was also raised as to whether serious trouble should be taken to save a child with a severe disability.

The second aspect concerns the open discussion of the *damage caused*. The dilemma method explicitly defines the damage accompanying certain choices, e.g. exploring the consequences of giving the patient chemotherapy or not. Treating her with chemotherapy would threaten the child's development, demonstrated by the following quote:

When everything started, it was still quite early in the pregnancy... And so all kinds of things can enter the equation, you know? At one time, I think, the idea was proposed of treating the patient with chemotherapy. Well... of course, that would affect the child's development. But even at that early stage, she didn't want to... to terminate the pregnancy. (Interview 3)

Giving nutrition via a feeding tube would also have prolonged her suffering:

Once it became clear what we were dealing with, a whole new set of dilemmas presented themselves. What to do? I still remember very clearly that the patient's mother came here for an appointment, saying gosh, she's starting to have trouble eating, shouldn't we try a feeding tube or something? And those were things that I really did have trouble committing to, because they would actually only prolong her suffering. (Interview 6)

As care professionals, the respondents feel a responsibility to explicitly name the damage during MCDs. Opting for the patient's desire to bring the child into the world and moving the birth forward would affect the child's chances of survival. But if it does survive, they run the risk of leaving the father with a disabled child:

She really wanted to carry the baby to term, and her final goal in life was to bring that child into the world. But she had had so much medication for her operation and her brain tumour, and the child just wasn't growing properly. (-) Were we supposed to take the child out far too soon? (-) Half of all children born under 26 weeks never make it anyway, and those that do survive are severely disabled. Should we really do that to the father, who is all alone in the world and with a family to care for? To lose his wife, and then be left with a disabled child? But fair enough, that's what she wanted. (Interview 4)

The third aspect is that of *putting oneself in the situation*, which involves the participants concretely imagining what is going on. They see a real picture of a woman lying there, with a tumour growing out of her head. The respondents stated that this allowed them to easily feel the tragedy of the situation, which can sometimes evoke memories of earlier, personal experiences, as relayed by the following interviewee:

An important fact to realise is that my mother also died of a brain tumour at her [the patient's] age, leaving similar-age children behind, so I had a very clear idea of what it was like. It meant... of course you feel emotional, but I was still able to keep a distance, I wasn't overly affected. Familiarity with the situation meant that I could contribute and that I had something to offer, like what is important for your children, what do you want them to remember, and letting go... (interview 10)

The fourth aspect concerns *insight into the perspectives* of the others involved. Because MCD examines the dilemma from a variety of angles, participants can reflect on their own motivations and those of others:

I was very grateful that we always discussed the matter as a large group. Everybody who was involved, the GP came, the neurologist, neurosurgeon, the clinical ethicist. The situation was viewed from all angles. (Interview 4)

The exchange of perspectives within a multidisciplinary setting raises understanding of the situation, and helps create a support base for the ultimate decision to be made in the dilemma. Taking the decision carefully and in consultation with others helps the MCD participants to move forward.

The fifth and final aspect relates to the *weighing up of values*. MCD places the emphasis on moral aspects, whereas treatment plans are drawn up and discussed according to established medical guidelines. The course taken by MCD discussions differs from those of a purely medical nature—the structure and guidance provided by the facilitator in particular help to get to the heart of the matter:

It was much more about the various moral aspects involved, and examining them together in a very structured way. Because moral deliberations are not part of our day-to-day, (...) I found it a very good approach. It brought me a great deal of clarity (...), the heart of the matter (...). I found the structure very helpful, and also the presence of a facilitator with a neutral, objective stance (...). I think all of the specialists would have appreciated it. We do each tend to look at things from our own little corner, after all. (Interview 4)

Making the values and norms explicit that play a part in the dilemma exposes the conflicts, revealing the tragic aspect of the case:

The extra dimension of MCD? Well, because, let's say, it was about... usually things are pretty clear, a child either has a defect or it doesn't, and you decide to treat it or you don't, and when it should be born is all pretty clear, but here there were two significant interests involved that, um, let me put it this way, the interests complicate things, the conflict of interests is more pronounced. Deciding against one thing will put the other at a disadvantage, so to speak. So deciding not to treat the mother will also reduce the prospects for the child. (Interview 1)

#### What do people need in tragic situations?

The respondents were asked what it is they need when confronted with a tragic situation. Five elements proved to be important. The discussion of these elements also looks at the question of the extent to which MCD in its current form meets the needs of the participants in tragic situations. The first point identified by the respondents concerns the *opportunity to share and discuss* the thoughts and feelings elicited among care providers by tragic cases. According to respondents, expressing and sharing the emotions evoked by a tragic situation requires greater attention:

The topic should be more open for discussion, I think. But I also believe that professionals should be trained to deal with it. I mean, aside from the emotions involved and the horrible events surrounding them, that it doesn't automatically mean that you can no longer do your job as a professional or that you need to take extended time off or whatever, but that you learn how it is (...) possible to live with it and retain sufficient confidence in your own ability to continue working as a professional. I would be in favour of that. (Interview 1)

The interviews revealed that MCD is helpful in tragic situations because it provides the opportunity to discuss *matters that touch people*:

(...) certainly in all of the MCD meetings too, and especially during the final session when we wrapped things up. Because there had been informal communication that she had died, but we didn't see one another then, and I did find it important to give things a proper conclusion, a fact that came out strongly again during that meeting. And the one who was most deeply involved, that was [midwife's name]. Because she's, she can also describe the family really well. She also went to the funeral, and is good at telling how it all went, with a great deal of attention. (-) That's why she was so touched by it all. (Interview 8)

MCD participants sit in a circle, which facilitates the sharing of experiences. During clinical discussions, the participants are often seated side-by-side, facing a screen showing projections of the case data:

After that, when the scans were available and the diagnosis had become clear, we had a meeting in one of those rooms with... a radiology room I think it was, a really big room with all the test results shown up the front using the projector. But everybody was sitting side-by-side, and we were right up the back, so we were mostly looking at people's backs, people did turn around... (Interview 10)

The second point is *care for oneself and for each other*. Tragedy has a major impact, and flips a switch in those involved. Especially within the context of an academic hospital, where all of the complex and serious cases from the region converge, and where doctors and nurses therefore see a lot of tragedy.

Firstly, care for oneself is one important aspect of dealing with tragedy:

So, when something like this happens, it's important for you as a person to have a support network. Of course there are your immediate colleagues, who don't necessarily need

to discuss all the details of the case, but more like gosh, how are you going to process that? (...) That's the inner circle of course (...). But besides that it's also very important for people to have lots of extra circles – family and friends – to provide support, like, if it's something that will be affecting you for longer than the average patient in an emotional sense. If you hit a roadblock or... then do you think that... your professional life will keep going well? Not for long. (Interview 9)

Secondly, it is important to *care for one another*. Tragedy places great demands on those involved, as demonstrated by the following quote from the sonographer:

I went to do the ultrasound, and I was pregnant myself. (...) Everyone really was a little worried about me. I remember that the professor of neurosurgery even gave me a phone call, that was very thoughtful of him. And a week later, during my visit to the clinic, they asked "And? How did it go?" And: "It was so brave of you to go do it." That was really nice I thought. And one of my colleagues also came along with me. She said yeah, you can't go by yourself. So in that sense there was (...) plenty of support. (Interview 4)

The third point identified as important by the respondents was *need for structure*. The purpose of structure when talking about tragic situations is to prevent participants from getting mired down in the emotional discussions elicited by the tragic case. The facilitator plays a key role in this respect:

The idea was certainly to arrive at a decision according to a schedule. And I think that MCD – especially when facilitated by someone who knows what they're doing – also means you don't get bogged down in all manner of emotional or other discussions; it may sound a little clinical, but not staying on task and making a decision... I think it was achieved in a very structured way. (Interview 6)

The structured nature of the MCDs also raised questions. Two of the respondents did not feel supported by the method:

And the pros and cons, that sort of thing you know, it was all forced into a kind of mould, and I thought, I actually thought it was a little unnatural. Those pros and cons, we're already doing that in our own heads, continually actually. (...) I actually found it a little contrived, the pros and cons, yeah it... And then you even need to sit down and formulate everything. (Interview 5)

A fourth point concerns attention to emotions. One respondent perceives MCD as a 'rather businesslike discussion', and believes that discussions of tragic situations should include more opportunities for *emotional reflection*.

I can well imagine that you...that it would be good to be able to discuss certain emotions more easily (...) because it's a rather businesslike discussion after all, those norms and values. Behind norms and values are always emotions, of course. And that, it might be a good idea I think, to provide that opportunity, from a certain perspective of reflection, so to speak. (Interview 1)

*Humour* is also important for dealing effectively with tragedy:

I think that there should be room for the emotional side of what we do and the cases we encounter, (...) so that includes the humorous aspect. Humour is also very important, which means the other side as well. So it's, that aspect should be included too. Even hospitals need a bit of normality. Normal people, actually using your ordinary eyes to keep looking at people, who just happen to find themselves in an awkward situation. (Interview 5)

In addition to the necessary attention to emotions, respondents also talked about the importance of *reflecting on one's own attitude to life*. MCD should target attitudes related to life problems, and contribute to the examination of personal motivating factors:

Yeah, and formulating your view of big life questions. Hard ones... (-) Yeah, life, um, problems that present as a part of life. Like, what is your attitude to them. How do I see them? How critical am I, and why am I critical? What are the important factors? Is it my emotions, my beliefs, is it culture? Is it my ignorance? My insecurity? What, what is it? What motivates me? (Interview 7)

A fifth point is the fact that people want to *learn* from the case, particularly with respect to similar future situations. For this reason, the respondents say it is useful that the case was discussed not only during MCD meetings, but also in casuistry discussions with gynaecologists, paediatricians and midwives from the local region:

Yeah, because I think it's, there's a valuable learning experience here for doctors in various stages of their training, (-) because what you want to avoid is for this to become a sort of (-) story that's whispered in the corridors, you know? She's a very ill patient in a very complex situation, with aspects that you want to put into perspective for all those involved. The story shouldn't do the rounds at drinks sessions. It's just, yeah, a very complex medical problem. And the thing you notice about trainee doctors is precisely the emotionally charged aspect, which of course means that they want to discuss it with everybody they believe can help them, and I think it should be given a proper forum, not like "Did you hear about that patient? Well listen to this...", no. But holding in-depth discussions with those around you in order to find a way for yourself to deal with things and to make decisions and so on, I think that's the way to get the greatest learning benefit out of the situation. (Interview 9)

## Discussion

The text above constitutes an investigation into the possible contribution made by moral case deliberation in dealing with tragic situations. The interviews revealed five key elements of tragedy: the 'lingering' nature of the case, the experience of intense sadness, acceptance, powerlessness and the threat to human dignity. Tragedy also proved to be evinced by the following five aspects during MCD: formulating the dilemma, explicitly stating the damage, putting oneself into the situation, insight into others' perspectives and weighing up different values. Lastly, five points for attention were highlighted for dealing with tragedy, namely: sharing with one another, care for oneself and for each other, a need for structure, talking explicitly about emotions, and learning from the situation.

The results have shown that a key feature of the tragic situation in the present case study is its tenacity in the memories of the healthcare professionals. This element of tragedy is addressed from the perspective of the ethics consultant in the book titled 'Cases that haunt us', which states that tragic cases "(...) linger in the memory" (Ford & Dudzinski, 2008, p. XVIII). Those involved learn that "They should be conscious that, often enough, they are working around (-) irreconcilable conflict" (p. XVIII).

The results may give rise to the question whether there is a difference between tragedy and moral distress. Although both may involve similar experiences, the crucial difference is that in the case of moral distress the healthcare professional knows the right action, but is prevented through external or internal reasons to act in accordance (Pauly et al., 2012), whereas in the case of tragedy there is no really good choice, since both alternatives come with moral damage.

The other four characteristic elements of tragedy (intense sadness, acceptance, powerlessness and human dignity) are all ripe with existential elements (Alma, 2005; Browall et al., 2014; Kenny, 2006). The existential aspects of tragedy are all linked to the inherent disconnect between what humans believe they can actively bring about (agency) and external events, or what is fixed or coincidental (contingency) (Nussbaum, 2001a). Health, friendship, love and possessions are all valuable things, but they also render existence vulnerable. Many things in life cannot be managed or controlled. Sometimes there is no option other than to live through and endure the situation.

The results show that MCD helps people to deal with contingency. MCD as a specific from of Clinical Ethics Support (CES) differs from Clinical Ethics Consultation (CEC). In CEC, the ethicist acts as a consultant, who reads the medical files, speaks with those involved, searches for a solution given the situation all heard. (Aulisio et al., 2000; Tarzian & ASBH Core Competencies Update Taskforce, 2013) The moderator in MCD only facilitates the process. In MCD the focus is on dialogue and reflection among the participants. Because the interest of the patient is paramount, it is recommended that the patient or his/her

representative is present during the MCD meeting. This was not possible in this case because of the severe illness of the patient.

Reflection happens first of all through the formulation of the dilemma and explicitly stating the damage, demonstrating that there is no simple solution in terms of agency. The reflection and dialogue during MCD supports healthcare professionals in the difficult decisions they face. In tragic situations, people need to accept that the ultimate solution will always also cause some damage (contingency), which poses a threat to one's morality.

This is also addressed by putting oneself in the situation, a process that is aimed at helping people to visualise the situation, and which brings back memories of personal experiences among the respondents. Visual images lie at the core of recollections of traumatic events (Janoff-Bulman, 1992, p. 55). Personal memories of confrontations with suffering and death provide a basis for reflecting on one's own values and life questions. Although healthcare professionals are confronted with patient suffering and death on a daily basis, reflection on life questions is not a part of medical training programmes. Visualising tragedy is in this sense like entering uncharted territory, and can be identified by the term 'deterritorialisation' (Deleuze & Guattari, 2003, p. 381). Moral case deliberation can open these images up for discussion.

According to Liaschenko et al. (2006), the link to one's own moral experience is crucial for adequately dealing with tragic situations in health care. When discussing tragic casuistry, medical students are often distanced from the case: it is analysed and 'solved' through the application of principles, and students are allocated the role of 'observer'. Liaschenko et al. point out that focusing on a solution (an attitude that, according to Nussbaum, is evidence of agency) distracts from the search for a moral stance. In education, being open to one's own doubts and learning from each other is key.

The results of this study show that, unlike standard discussions about patients, MCD prompts participants to formulate and share personal experiences with one another and thus helps to create a shared perception of the situation as both tragic and contingent.

The respondents identify various needs when dealing with tragedy. First and foremost is the need to share with one another, for which MCD provides a solid basis. In MCD sharing and recognizing each other's struggles and concerns creates a mutual bond. Analyzing values may contribute to mutual understanding (Molewijk et al., 2011b). Respondents also indicate a need to care for themselves and for each other. This care is not provided during MCDs themselves, but participating in MCDs fosters a climate of support. The exploration of what people need in tragic situations is also addressed in other disciplines (Benson & Magraith, 2005; Collins & Long, 2003; Janoff-Bulman, 1992; Renzenbrink, 2011). These studies show the importance of colleagues who attend to each other's wellbeing and the importance of talking about thoughts and feelings in a safe environment

(Collins & Long, 2003; Johnson et al., 2004). In Balint group work for health care professionals the doctor-patient relationship is discussed and peer support is provided. Participation in Balint group work has the potential to prevent fatigue and burnout in participants (www.americanbalintsociety.org). Yet, MCD is different from psychological support or Balint group work, as "addressing emotions in MCD focuses [...] on a deeper conceptual insight and a personal learning process regarding the moral issue at stake" (Molewijk et al., 2011b, p. 392).

Thirdly, respondents stated a need for structure. Respondents value the structured approach of moral case deliberation, as it gives depth to the dialogue. Structure fosters insight into values and norms, and is important for moral learning. However some respondents noted that the structure must not take on too much of a 'schoolroom' character—the conversation should entail more than mechanically 'filling in the blanks' between pre-defined elements. The structure should encourage reflection, inquiry and dialogue among the participants (Weidema et al., 2013). MCD aims at moral learning. The facilitator plays an important role in the learning process of the participants, by assisting them in focusing on and exploring moral aspect of the case (Stolper et al., 2016).

Fourthly, moral case deliberation should devote attention to the participants' emotions and ethical attitude to life. Emotions are evidence of norms and values (Nussbaum 2001b), and of the things that matter in life. To date, the role of emotions in moral case deliberation has been discussed very little in the literature (for exceptions, see Molewijk et al., 2011a, b). The above-mentioned disconnect between agency and contingency means that emotions are of key importance. Because emotional reflection during MCD highlights values that help to steer the course of action to be taken, aspects of contingency can shed light on what kind of agency is important. Contingency and agency remain at odds with one another, however reflecting on contingency can help to clarify what is at stake when taking action, providing an indication of whether action is required, and if so, what kind. Humour, which the respondents mention as important even in this case, plays an important role in cases of tragedy (Collins & Long, 2003; Taels, 2008). It helped the participants to see the patient not as an object of medical treatment, but as a subject, a human being needing help. In addition to emotional reflection, the results also suggest reflection on one's own attitude to life as a point for attention. Tragedy means being confronted with life questions, a situation in which cultural and religious aspects can play a role.

One final point relates to learning from the experience of a tragedy. This learning has both a medical and an ethical dimension. Deriving learning from the situation has a two-pronged effect: it helps to acknowledge and accept the contingency, and prompts consideration of whether the insights gained can be used to improve future decisions. This way, moral case deliberation offers a platform for moral learning through investigating the relationship between contingency (powerlessness) and agency (responsibility). It teaches people to explore the values hidden in the contingency, thus facilitating targeted decision-making.

# Conclusion

Tragedy concerns essential aspects of life, such as suffering and death. It puts life into perspective, and brings an awareness of what is truly important. As Janoff-Bulman says: 'They have made their peace with the inevitable shortcomings of our existence and have a new appreciation of life and a realization of what is really important' (1992, p. 175). In addition to the emotional burden on those involved, tragic situations also demand attention to existential ideas in order to deal with tragedy as it is.

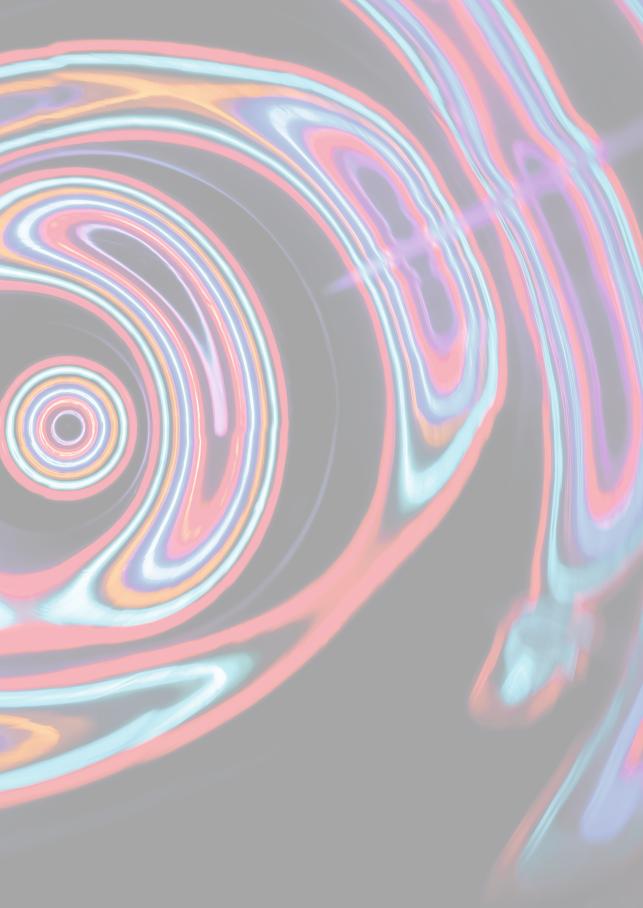
Moral case deliberation facilitates sharing the experience of tragedy, and the ability to manage the five elements raised by tragedy. MCD helps to define the contingency in tragic situations. Formulating a dilemma, explicitly stating the damage caused, insight into others' perspectives, putting oneself in the situation and visualisation prove to be important tools for gaining an understanding of personal norms and values and searching for a moral stance. Tragic situations present a combination of contingency and agency. MCD in tragic situations could be improved through an awareness of not only the medical and moral, but also the emotional and existential concerns present in the case and during the MCD sessions. Effective incorporation of these concerns in MCD and explicit reflection on the contingency aspect of tragedy will improve participants' ability to accept and morally learn from the situation, and to forge a path through unknown territory. In this way, moral case deliberation can help participants come to terms with the dilemmas they experience when having to work around an irreconcilable conflict.

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Tragedy in MCD



# 3. Addressing harm in moral case deliberation: the views and experiences of facilitators

Keywords: Tragedy | Moral case deliberation | Decision-making | Harm | Repair

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# Abstract

## Background

In healthcare practice, care providers are confronted with decisions they have to make, directly affecting patients and inevitably harmful. These decisions are tragic by nature. This study investigates the role of Moral Case Deliberation (MCD) in dealing with tragic situations. In MCD, caregivers reflect on real-life dilemmas, involving a choice between two ethical claims, both resulting in moral damage and harm. One element of the reflection process is making explicit the harm involved in the choice. How harmful are our decisions? We investigated how facilitators of MCD experience the importance of addressing harm in MCD and what participants learn from reflecting on harm.

#### Methods

The study was qualitative, focusing on the views and experiences of the facilitators of MCD. Semi-structured interviews (N = 12) were conducted with facilitators of MCD. The research focuses on the subjective experiences of facilitators. Grounded Theory was used for analysis.

#### Results

The results show two main categories. The first concerns the awareness of tragedy. Within this category, five themes were discerned: making explicit that there is no solution, visualizing consequences, uncovering pain, focusing on emotion, and exploring perspectives on harm. The second category concerns the support for healthcare professionals in dealing with the tragedy of the choices they face. In this category, five themes came forward: acknowledging, offering comfort, managing harm, consideration through dialogue and repairing harm.

#### Conclusion

Our study shows that addressing harm in MCD in tragic situations provides an important moral learning opportunity for participants. By formulating and becoming aware of harm, MCD aids healthcare professionals in the task they are faced with, namely making difficult and painful choices. MCD helps healthcare professionals to repair moral damage, making clear at the same time that harm cannot be undone.

## Background

Healthcare providers are often confronted with tragic situations. Examples are: Should we stop treating a young woman who has suffered a severe cerebral haemorrhage and slipped into a coma? Should we keep a seriously ill baby in the hospital who has been there for months with no hope of recovery, or discharge the baby, so that it will die at home? Can a scheduled operation be postponed a third time? In such situations, healthcare professionals face a dilemma. The choice they make will inevitably be at the expense of the alternative – every choice causes harm.

In healthcare practice, Clinical Ethics Support (CES) is available to support professionals in making difficult ethical decisions. Moral Case Deliberation (MCD) is one of the instruments applied in CES (Dauwerse, 2014, pp. 43-63; Molewijk et al., 2008; Stolper et al., 2010; Weidema et al., 2013). The aim of MCD is not to provide expert advice, but to facilitate reflection (Stolper et al., 2016; Dauwerse 2014, p. 10). During MCD, healthcare professionals involved in a concrete situation jointly investigate moral issues in healthcare (Molewijk, 2014, p. 34. Studies have been conducted on goals (Dauwerse, 2014, pp. 43-63), practice (Stolper et al., 2016), implementation and impact of MCD (Svantesson et al., 2014; Seekles et al., 2016). However, little research has been conducted on the role of MCD in dealing with tragic situations (Spronk et al., 2017). An important element in MCD is making explicit the moral damage and harm that a choice entails. Identifying the harm in a moral dilemma is a fixed part of deliberations run using the dilemma method. By identifying the potential harm, the tragedy of the case is put 'under the magnifying glass'. Little attention however is given to what the professional has to give up, when a course of action is chosen in a dilemma. The research question addressed in this paper is: How can MCD support healthcare professionals in tragic situations by addressing this harm?

In our concept of harm we follow Nussbaum (2000; 2001a, p. 25). Harm concerns the moral damage that cannot be avoided or resolved. This differs from the four principles approach of Beauchamp and Childress including the non-maleficence principle 'one ought not to inflict evil or harm' (Beauchamp, & Childress, 1994, pp. 190-193), often used in Ethics Consultation. In Ethics Consultation harm is a topic of reflection in weighing up beneficial and nonbeneficial effects (Montaguti et al., 2019; Reiter-Theil et al., 2018). Doing so requires balancing the outcomes and choosing the best solution (Beauchamp & Childress, 1994, p. 291). Following Nussbaum, whatever option one chooses, a fundamental moral damage remains, which cannot be resolved, but needs to be acknowledged. This notion of harm is addressed in this paper.

Literature on tragedy often focuses on experiences of patients living with a serious illness, trauma or disability (Callister, 2018; Fletcher, 2018; Iacobucci, 2018; Kmietowicz, 2018; Rosenbaum et al., 2017; Siebert & Drezner, 2018). Sometimes, literature addresses the burden experienced by healthcare professionals due to the difficult decisions they face, and their

consequences (De Vos-Broerse, 2015; Ford & Dudzinski, 2008). In this article we examine the role of MCD in supporting healthcare providers who are confronted with tragic choices.

MCD sessions are guided by trained facilitators, whose experiences with MCD constitute a source of knowledge. We therefore aim to tap into their views and experiences of addressing harm. We will also examine whether and, if so, how making harm explicit supports professionals in dealing with tragedy.

We will start by defining the concept of tragedy based on the literature, followed by a description of the research method applied and the results obtained. The discussion will reflect on the results, after which a conclusion will be provided.

#### The concept of tragedy

Tragedy relates to the vulnerability of life (Nussbaum, 2001a, p. 399). Tragic situations require choices that involve suffering and death. These choices are often accompanied by feelings of powerlessness, and entail threats to human dignity (Spronk et al., 2017). If there is any place where such situations abound, it is in hospitals.

Care providers often have to take decisions that will result in harm no matter what they choose. Nussbaum draws a distinction between situations that can be resolved by a cost-benefit analysis, and those that involve deciding what to give up. She refers to the latter as 'the tragic question' (Nussbaum, 2000).

According to Nussbaum, the greatest challenge lies in the moral choices that people are thus forced to make. These she refers to as 'the tragic conflict', and they are considered tragic because they force action in situations where each available choice is accompanied by inevitable moral objections.

In such cases we see a wrong action committed without any direct physical compulsion and in full knowledge of its nature, by a person whose ethical character or commitments would otherwise dispose him to reject the act. (2001a, p. 25)

Nussbaum argues it can be beneficial to reflect on such situations, as they force us to consider what constitutes 'personal goodness'. Nussbaum has studied the Greek tragedies extensively. As an example of a tragic conflict, she cites Agamemnon who must choose between abandoning his expedition to Troy, or sacrificing his daughter. The gods put him in this situation, and there is no escape without acquiring blame (p. 34). However, Agamemnon supposes that there is a proper course of action – the lesser of the two evils (p. 36) – and he does not see the harm caused by choosing that course. The chorus reproaches Agamemnon for not acknowledging the severity of his deeds, for showing no remorse, and for accepting them as pious and just (p. 35). According to Nussbaum, we must acknowledge the harm that will always exist on both sides of the dilemma.

In summary, tragedy occurs when both choices in a dilemma have morally bad consequences. Treatment providers are expected to make these types of decisions when treating vulnerable patients who face the prospect of illness, suffering and death. These choices affect professionals in their working life and their personal values. While we do not want to trivialise the impact of tragic situations on patients, this article will focus on the tragic conflicts faced by healthcare providers.

#### Moral case deliberation and the dilemma method

Moral Case Deliberation (MCD) is a structured method for investigating a moral issue experienced by participants in practice. It is guided by a trained facilitator. MCD participants are often healthcare professionals (doctors, nurses, paramedics), but can also include managers, family members or patients themselves. The principal element is a case presented by one of the participants. The case must entail a concrete, personal experience from the past or present – not a hypothetical situation (Stolper et al., 2016).

The main aim of MCD is not to arrive at a solution, but to jointly explore the ethical question at hand and thus encourage critical reflection on the values associated with the concrete facts of the case (Stolper et al., 2016). The reflection is brought about by dialogue. Dialogue is a teaching method involving the exchange of various perspectives in order to arrive at a 'fusion of horizons' (Gadamer, 1960) among the participants. The purpose behind exchanging perspectives is to search for common ground between one's own and others' experiential horizons, in order to understand one another better and get a richer view of the situation.

To structure the discussion, the facilitator uses a specific conversation method. A wellknown method is the dilemma method (Molewijk & Ahlzen, 2011; Stolper et al., 2016), which formulates the ethical issue as a dilemma, presented as two mutually-exclusive treatment options. The dilemma method entails the following steps: 1. Introduction; 2. Presentation of the case; 3. Formulating the moral question and the dilemma; 4. Clarification in order to place oneself in the situation of the case presenter; 5. Analysing the case in terms of perspectives, values and norms; 6. Looking for alternatives; 7. Making an individual choice and making explicit one's considerations; 8. Dialogical inquiry; 9. Conclusion; and 10. Evaluation (Stolper et al., 2016).

In this method, moral damage or harm is explicitly addressed in two of the steps: first in step 3, when the dilemma is formulated and the negative moral consequences of both options are made explicit; and second in step 7, when participants are asked to make an individual choice and to specify how they might repair the harm related to that choice. The dilemma method is thus in line with Nussbaum's concept of tragedy discussed above. Other methods can also be applied to facilitate MCD (Van Dartel & Molewijk, 2014). In such methods, the harm associated with the moral decision is not always explicitly addressed.

# Method

## Data collection

Semi-structured interviews were held by the first author with MCD facilitators, who were asked to give examples of MCD sessions run by themselves that involved a tragic situation, and to explain them briefly. Facilitators using the dilemma method were asked about the role of addressing harm in the MCD. Respondents who do not use the dilemma method were asked how the aspect of harm is brought up in their own method. They were also asked for their opinions on the explicit identification of harm in the dilemma method.

The following criteria were used to select facilitators:

- Extensive experience in MCD facilitation (a minimum of one year's experience as a facilitator);
- Currently working in healthcare (a hospital, psychiatry); and
- A representative distribution in gender, age, professional backgrounds and fields of operation.

Twelve facilitators were interviewed (six male and six female) at their workplace or at their home. A procedure of purposive selection was followed. As the respondents were known for their experience in MCD, they were asked by email to participate. No one refused. The respondents included two clinical ethicists, three spiritual counsellors, three medical specialists, one paramedic, two healthcare managers, and one nurse manager, thus spanning a wide range of educational backgrounds. The respondents worked as facilitators with various groups. Six worked in hospitals, three in mental healthcare, and three in both. The age of the respondents ranged between 30 and 68 years. The facilitators used a range of MCD methods: eight used the dilemma method, next to other methods, four only used other methods. These methods entail value clarification and the Socratic dialogue. Although these methods are similar in reflecting on an ethical case, they do not take the ethical dilemma as a starting point for the deliberation.

After obtaining the respondents' consent, all interviews were recorded, transcribed, and de-identified by the first author and an assistant. The VU University Medical Centre's Medical Research Ethics Committee declared the study did not fall under the Medical Research (with Human Subjects) Act (WMO), as no interventions were performed.

#### Data analysis

The study aimed to identify the key elements of addressing harm as part of MCD, based on the facilitators' personal experiences. The facilitators' experiences were defined as broadly and openly as possible. To this end, we made use of the Grounded Theory approach as developed by Charmaz (2006).

Data analysis was carried out in three stages. The first stage involved open coding: the first two interviews were coded independently by two researchers, and the results compared in order to establish inter-rater reliability. The results were discussed by all three authors. Based on this process, the topic list for the next interviews was refined. The next two interviews were coded by the first author, after which the three authors reflected on the resulting coding tree, in order to foster validity. The first researcher then conducted another eight interviews, two of which were also coded by a research assistant to again establish inter-rater reliability.

During the second stage, focused coding, eight interviews were analysed, and codes were clustered into overlapping themes. The results were discussed by the first two authors deciding on the best phrasing of the themes. This produced ten over-arching themes, formulated as 'gerunds' in accordance with Tweed and Charmaz (Charmaz, 2006; Tweed, & Charmaz, 2012). Gerund-based coding ensures a focus on actions rather than concepts, retaining a closer connection to the data (e.g. 'visualising consequences' instead of just 'consequences'). This approach suited our study, as we sought to investigate how harm was actually addressed in MCD practice.

The third phase – axial coding – examined the relationships among and patterns between the various themes, after which the over-arching themes were refined and the final categories formulated. After the full analysis of eight interviews, theoretical saturation was reached. We analysed the other four interviews, with participants from various backgrounds. In the analysis no new themes were found.

## Results

The section below describes the categories and themes identified. They derive from multiple cases. Examples are forced treatment versus private integrity, the request of relatives to continue treatment versus the professional account that prolonging treatment is medically useless and adds suffering (and vice versa), stopping or continuing treatment in the neonatology ward and rights of potential parents versus the rights of the child in fertility treatment. A summary of the categories and themes is given in Table 1.

Category	Theme
1. Awareness of tragedy	Realising that there is no solution
	Visualising consequences
	Uncovering pain
	Focusing on emotion
	Exploring perspectives on harm
2. Dealing with tragedy	Acknowledging tragedy
	Offering comfort
	Managing harm
	Consideration through dialogue
	Repairing the harm

Table 1. Summary of the key elements in addressing harm

#### Awareness of tragedy

The first category is the awareness of tragedy, and covers multiple themes.

#### Realising that there is no solution

In the first place, identifying harm can help MCD participants realise that there is no solution. This is exemplified in the following quote:

I do often bring it up myself... and it does help... It helps because sometimes people are still trying to avoid harm completely, they are looking for the best solution. And it just helps to actually confront the reality, that it's just not going to happen! (Interview 5)

#### Visualising consequences

In the second place, addressing harm makes the consequences of both options visible, and shows what is at stake in the dilemma.

I think that formulating the harm really helps drive home the implications and consequences of the treatment options to the participants. So it always helps, because it reveals what is at stake. (Interview 1)

One of the most important things in her case, and the MCD that really helped her, was creating the overview of the negative consequences of her decision. [...] She really hadn't considered any of the adverse effects or the potential harm, she just thought she could deal with the situation. It was an important thing for her to realise. (Interview 7)

One respondent mentioned a downside of focusing on negative consequences; according to this respondent it can sometimes be helpful to identify the main benefits of each option, instead of concentrating on the negative consequences.

People sometimes ask why I never list the positive aspects of each side in the dilemma. 'Good question' I think! But we do it this way anyway, because of the tragic character of the situation. But sometimes I also think to myself, yeah, in certain situations it could also be really useful. So instead of the harm on each side of the dilemma, [...] we could look at what would be the best reason to go for option A, or what the greatest benefit would be. (Interview 5)

A limitation of visualizing consequences is that they are not yet real during the MCD, but only surface later.

And at that moment, the biggest fallout resulting from the decision is invisible to the participants in the MCD. Because either the people trying to get pregnant don't get help, [...] we refuse to start treatment. So that's one potential form of harm. But we could also agree to treat them, and then their child could have some serious condition, but we wouldn't see that either if it did happen. (Interview 9)

#### Uncovering pain

Addressing harm exposes the pain involved in the dilemma:

We find it hard to make a choice, because we see that choosing one thing will bring about consequences that are also painful and difficult. (Interview 6)

It's a very useful way to talk about harm, for parents too. [...] Because in a situation like this, they are of course dealing with a huge amount of pain. (Interview 2)

A possible downside noted by one respondent (who does not use the dilemma method) is that the pain thus uncovered is magnified. For this reason, this respondent explores the moral values of those involved, without explicitly asking for the harm.

No, we don't insist on people listing the harm. [...] What we do is explore the values of those with a moral stake in the situation. (Interview 6)

This respondent associates harm with waddling in despair.

So should we explicitly dig and ask, what kinds of horrible things will happen if we do such and such? That's not how I work! No way. (Interview 6)

#### Focusing on emotion

Addressing harm also entails focusing on emotion. Identifying harm shows how people are moved by the issue.

We look at A and B, then formulate the dilemma, and then the harm on both sides. So it's usually inherent to the method, in which case it is often expressed emotionally. If someone starts off saying, no I can't, I can't simply stop treatment if there are still options available (talking about the harm of option A) or whatever it is, then you see the harm emerging very clearly. (Interview 5)

A downside noted by some respondents is that the focus on emotion through identifying harm can stand in the way of reasoning and deliberation.

And once you find yourself in a tragic situation, it's hard to keep a clear head. And why is that? Because you get so caught up in your visceral and emotional responses that you can't separate yourself from them anymore, sometimes not for years! That's how tragic these things can get. But the shift, there should be a shift towards: 'What do I actually think?' Why do I keep wallowing in the tragedy? (Interview 7)

We're only human and these things touch us deeply. And that, I think, is the important thing about our moral sensitivity, that it is touched, because that's what the facilitator is asking for. [...] You mustn't shut out your emotions, but emotion shouldn't be the primary focus. (Interview 4)

## Exploring perspectives on harm

The fifth theme involves exploring perspectives on harm. Asking participants to make harm explicit during MCD creates insight in other MCD participants' views on harm.

Well, I do think it helps clarify things for the participants, and helps them understand what other people see as damaging. (Interview 9)

Yes, I ask them about it (the harm) point-blank, because I think it's necessary to achieve the second goal of MCD, which is understanding each other better. (Interview 11)

The various perspectives of the care provider, patient and family on harm are all included in the discussion.

When asking the question 'what constitutes proper care?' I think it's really critical to look at the resulting harm. Like if we decide on a certain course of action, what is it we're trying to avoid? And that might be our view as health professionals, but what do patients think? Or their families? I think it's very important. (Interview 10)

#### **Dealing with tragedy**

The second category relates to how discussing harm can help those involved to deal with tragedy.

#### Acknowledgements

In the first place, discussing harm can help to deal with tragedy through the acknowledgement of harm. In this context, attention to unresolvable issues and acknowledgement of long-term harm are important.

The loss or lingering remains of harm... sometimes it might even actually be helpful to spend some time thinking about that, about the things you can't resolve, the lasting effects, and to acknowledge them. (Interview 1)

Approaching and standing face-to-face with tragedy can make us feel very lonely. But the simple acknowledgement of 'it is what it is' can be tremendously liberating – and an enormous relief, because of the feeling of acceptance. There's no longer a need to fight it, to oppose it or to resolve it. The first step is to 'acknowledge what it is for a moment'. (Interview 4)

#### Offering comfort

Secondly, discussing harm provides comfort. Participants relate to the harm on both sides of the dilemma, which is why it is unresolvable. The facilitator's job is to be attentive of this. Certain things in life cannot be resolved or repaired, and making harm explicit can offer comfort or relief.

I think we all sometimes feel tempted to try to resolve a situation without causing any harm, whereas if you realise it's simply not possible, that you'll need to weigh things up, that there will inevitably be harm somewhere... it gives you peace, more peace of mind, more comfort, something like that. (Interview 5)

#### Management

Thirdly, MCD can equip and empower health professionals by making them reflect on possibilities to manage harm resulting from their choice in the dilemma.

First of all, exploring various perspectives on harm can help.

Of course, this case involved multiple types of harm, yes. And now that you mention it, there was a very nice turning point [...], when one of the doctors came out with a real eye-opener, he said: 'who are we to say (to the patient) 'too bad, you have yourself to blame, now here you are again after wasting six months'. Perhaps to him those six months weren't wasted? Perhaps they were worthwhile. (Interview 11)

Secondly, MCD can help to manage harm through reflection on the relationship between harm and living a good life, which can lead to the realisation that there is no such thing as a perfect life.

Suppose you've found the good life, a medically perfect life, you're home and housed... then what? That's when I asked all those critical questions I mentioned to the group. (Interview 11)

Thirdly, making harm explicit may equip and empower health professionals with management strategies. The investigation of tragic cases in MCD focuses on the question: What lies within my power? What resources can you draw on to help you realise it?

So at some point we might decide on something particularly horrible – what should we do? It's the lesser of two evils. The first thing I do is look at what you can draw on to help you. Have you been in a similar situation before? What worked then? Do you maybe know someone who can help you? And how can we check that it will work out? It's about giving people strategies, and empowering them. (Interview 6)

*Plus, I see MCD as a way of giving mainly health professionals, but others too, ways of managing and dealing with the type of tragedy that is inherent to our practical reality as well as they can. (Interview 4)* 

#### Consideration through dialogue

In the fourth place, harm can be considered in dialogue. Dialogue is important when seeking to establish why a certain course of action should be pursued. Such a dialogue can take place among colleagues, as evinced by the following interview excerpt:

Interviewer: So the weighing up is achieved through... RES: Dialogue! Interviewer: Through discussion in dialogue with one another? RES: So it's not like I say, how much is this worth and how much is that worth, and we do a little addition and subtraction and then we're finished, no. (Interview 6).

The dialogue may also involve a patient and/or their family.

We decided to turn off the respirator of a young woman who had suffered cerebral haemorrhaging. The harm in that case was the family's extreme emotional response, because as you can imagine, ceasing treatment based entirely on medical grounds is pointless. [...] And the way to limit the harm in that case was actually to enter into dialogue with them, to start a conversation and to give your reasons for making your decision and why there is no point in continuing with treatment. (Interview 8)

In this dialogue, weighing harm is not a matter of quantity – it is a personal consideration that others might make differently.

I think it's important to understand that it's not about quantity, it's not like this option is less damaging than that option so that's automatically the right answer. I also think it's important to realise that people weigh things up in their own way, and that for others the balance might fall differently. (Interview 5)

Respondents state that weighing harm is not a mathematical operation. Discussing the harm through MCD helps establish a bond among the participants.

There are times when you think... this is just tragic. There's no way out. It's actually quite heartbreaking, and a good thing that we all feel it together. That's the bond you feel as part of a tragedy. [...] Then something changes during the session, something that I believe is very powerful. In other words, I think using a kind of technical formula – 'we've got some pros and cons on the scales so this is what we're doing' – would be a missed opportunity. (Interview 2)

The subject of limiting harm is also addressed when searching for a middle ground.

I think it [the harm] is automatically included in weighing things up, perhaps also in looking at resolvability, or opportunities for limiting the harm. A week or two ago we ran an MCD here. [...] And ultimately we arrived at the same middle ground. Well, we still needed to check a couple of things. But all the doctors and nurses said 'we're doing A, provided we can be certain' and all analysts said 'we're doing B, unless there is evidence to the contrary.' (Interview 9)

#### Repairing harm

Finally, addressing harm as part of MCD helps the participants to deal with tragedy by looking at whether harm can be repaired.

That's a very important part of everything too, of course, that whichever option you choose, A or B (and sometimes there's also C or D), there will always be drawbacks. It helps to get them out in the open and to look at what can be salvaged, so to speak, at what extra things can be done to limit the harm. (Interview 3)

That's the unique thing about the method. MCD goes like this: you look at the situation, and make a decision between A or B. But any decision you make will always automatically cause harm. That's the tragic thing about dilemmas, there will always be harm, no matter what you do. But you can also look at how to keep it to a minimum. (Interview 8) One downside mentioned is the fact that it is not always possible to repair harm. Some of the respondents pay special attention during MCD on specifically identifying this type of harm, which cannot be reduced or eliminated.

So MCD is all about deciding between two evils. You identify the harm and then ultimately weigh things up: what the plan is, why that plan was chosen and how the harm can be reduced. But the harm that will always be there, that never goes away, is never listed separately, and that is an element I would like to add. (Interview 1)

## Discussion

Using the Grounded Theory approach, this study investigated the role of addressing harm as a part of MCD in discussing tragic situations.

Under the awareness category, the results first of all show that discussing harm in MCD can help healthcare professionals to realise that there is no ideal solution, a result that is in keeping with Nussbaum's viewpoint. Care providers must make a choice between two ethical claims, both of which result in loss. This can be explained further by referring to the example of the choice between stopping treatment and letting a young woman die or keeping her alive in a condition of unconsciousness, mentioned in the introduction. In such a situation, care providers experience the limits of their professional competence. The harm they have to deal with is not only the harm for the patient, but also the harm for the care professional feeling responsible for his choice. This differs from an (avoidable) error or mistake and concerns harm on a fundamental level.

Secondly, the results showed that putting the harm into words can help to visualise the consequences of both options in the dilemma, and to take stock of the negative consequences of a decision. Some downsides were also named: in addition to identifying the harm caused, respondents feel it would also be worthwhile to focus on the benefits of each decision. The second downside is that the harm can only be estimated and not fully assessed during the discussion. The facilitator can assist in this regard, by using the perspectives of all participants to examine the severity of the harm for each individual as effectively as possible, and to envisage the future impact and consequences of any particular decision together as a group.

Thirdly, putting harm into words helps to uncover the pain involved in the moral dilemma – both the pain experienced by patients and their loved ones, and agonising decisions that must be made by health professionals. This is reminiscent of 'moral injury' (Carey et al., 2016; Shay, 2014) and 'moral distress' (Epstein & Hamric, 2009; Fourie, 2013; Thorne et al., 2018). Moral injury "is present when (1) there has been a betrayal of what is morally right, (2) by someone who holds legitimate authority (in the military a leader) and (3) in a high-stakes situation" (Carey et al., 2016, p. 1219; Shay, 2012). Moral injury refers

to harm incurred in combat situations, where not only psychiatric but also moral harm is sustained due to people's experiences (Shay, 2014). Moral distress emerges 'when one knows the right course of action, but institutional or cultural constraints prevent one from pursuing it' (Jameton, 1984, p.6; Jameton, 1993). Harm in case of moral distress is addressed by Thorne et al. They state:

The ambiguity and complexity of many NICU cases mean that clinicians may inevitably be left, regardless of the professionalism of their actions, feeling that they may not have done enough, other options could have been followed, errors may have been made (Thorne et al., 2018, p. 697).

According to Thorne et al., a particularly effective way of combating moral distress in the NICU is to target the structural and cultural elements that cause it. MCD can help in this regard (Metselaar et al., 2017). In terms of moral distress, MCD differs in its approach by assuming at the outset that no satisfactory choice is possible, since both alternatives will be accompanied by moral harm (Spronk et al., 2017).

Fourthly, identifying the harm creates a focus on how people are moved by the issue. Baart (1993) argues that precisely these emotional responses show what agents find important. Decisions are not made based on general principles, but in concrete situations (Bontemps-Hommen et al., 2018). Rather than going unacknowledged, emotional bonds should be embraced to allow them to fill their respective agents with love, horror, pain or remorse. The emotions will reveal the proper conceptualisation of what is at stake (Baart, 1993, pp. 40-41). According to Rasoal et al. (2016), discussing ethical questions in MCD can help them better understand the associated emotions.

A possible downside in this is that emotions can sometimes eclipse the ethical issues, thwarting discussion. Emotions flaring too high could mean that conditions for reflection and dialogue can be hampered (Molewijk et al., 2011). However, reflecting on emotions is important, as they are indications of underlying values (Nussbaum, 2001b).

In the fifth place, discussing harm is important in order to acknowledge others' perspectives on harm. Getting the harm 'out in the open' creates understanding and clarity regarding what others in the MCD consider 'harm'. The various perspectives of the care provider, patient and family on harm are all included in the discussion. Exchanging perspectives as part of MCD is important (Stolper, 2016, p. 73). This can make people's views on harm change: by looking at different perspectives, the harm originally perceived by the care providers as a medically pointless procedure for the patient can change into 'a worthwhile period of time for the patient'.

The first theme identified under the category of 'dealing with tragedy' is the importance of acknowledging the harm. Putting the harm into words can help to provide comfort,

an effect that has been identified in psychology and trauma processing (Janoff-Bulman, 1992; Pratt & Jachna, 2015). Nussbaum arrives at this understanding through her literary and philosophical examination of classic works. For the context of healthcare, this is supported by Vosman and Baart (2011). Baart (1993) confirms the importance of devoting time to acknowledging tragedy. He believes it is important for care professionals who are confronted with tragedy to arrive at treatment decisions they can personally take responsibility for and be committed to (p. 34).

Secondly, comfort emerged as one of the resulting themes. Comfort is important, as tragic issues can be associated with feelings of guilt. Nussbaum states: "Asking the tragic question requires, first of all, assuming a possible burden of guilt and reparative effort, something people [...] do not always enjoy doing" (2000, p. 1017). The inability to comply with both important values but having to make a decision regardless means dealing with a possible burden of guilt and reconciliation with the choices made. According to Nussbaum (2000, p. 1017), acknowledging tragedy and confronting the part we ourselves play therein – though the harm may be unavoidable – motivates us to look at what we can do to repair the harm caused by our actions.

This is never entirely achievable, which reveals the tragedy of life itself, which is part of the world in which we live (Anbeek, 2018; Anbeek & De Jong, 2013; Dohmen, 2008; Schmid, 2001). This tragedy is part-and-parcel of our very existence (Drewermann, 1984, p. 77) and must be acknowledged (Bubmann, 2010; Krijger, 2005). It is important both to look at the residual harm that can be resolved, and at the irreparable, ongoing harm. This fact was reflected in the results, in which several respondents reported devoting greater attention to identifying the long-term harm.

Comfort can also relate to religion or spirituality, a topic which is not explicitly addressed in MCD. Further research is necessary on the potential role of addressing these aspects via MCD.

In the third place, putting harm into words helps professionals to manage tragedy, primarily through reflection on the various perspectives on what constitutes harm. Also, harm can be managed through reflection on the relationship between harm and living a good life. The MCD facilitator may encourage people to be aware that there is no such thing as 'the perfect life'. Moreover, discussing harm helps by equipping and empowering health professionals with strategies through a shift in perception from what cannot be changed (powerlessness/acceptance) to what can be changed (action). During MCD, the facilitator encourages care professionals to think about what they *can* achieve.

The above-mentioned aspects of managing tragedy can be related to the notion of resilience. Moral resilience is "the capacity of an individual to sustain or restore their integrity in response to moral complexity, confusion, distress or setbacks" (Rushton, 2016, p. 112).

According to Young, Rushton & Faan (2017), the emphasis on resilience emerged as a positive response to moral distress. In research among nurses, it has been shown that positive formulations and language are capable of altering the outcomes of situations that are known to cause moral distress. Putting harm into words can contribute towards a positive formulation, if it leads to experience-sharing and an examination of how harm can be mitigated. This technique can inform care professionals how they can manage harm, boosting their resilience.

Fourthly, formulating harm helps 'weighing up' through mutual dialogue, which is a significant component of MCD (Dauwerse, 2014, pp. 46-7). This is not a simple equation, based on pluses and minuses, but a personal exploration of the important underlying values.

Within the context of public-policy choices, Nussbaum states that cost-benefit issues and issues of tragedy can sometimes become entangled (2000, p. 1008). A cost-benefit analysis aims to uncover "a strategy for choice in which weightings are allocated to the available alternative, arriving at some kind of aggregate figure for each major option" (2000, p. 1028). Such a cost-benefit analysis looks not only at financial benefits, but also at the economic distribution of what is perceived as worthwhile. Tragic questions cannot be answered by a cost-benefit analysis (Nussbaum 2000). The consideration is not an addition or subtraction sum, nor is it an economic rationale. Our results support this conceptualisation.

The aim of addressing harm during the MCD discussion is to draw out the underlying key values at play, which helps health professionals to make the necessary choices – choices that are ultimately about what it means to them and their patients to live a good life. Formulating harm not only raises awareness of vulnerabilities and highlights the negatives; it shows that harm also reflects what people hold dear and consider valuable in life (Anbeek, 2013; Nussbaum 2000, pp. 1035-1036). Our results show that discussing harm through dialogue can create shared bonds.

When weighing up the options, the participants in the dialogue look for opportunities for reducing the harm. Nussbaum argues that it is valuable to investigate the basic assumptions underlying the dilemma itself. We should always ask ourselves Hegel's question: "Is there a rearrangement of our practices that can remove the tragedy?" (2000, p. 1016). Taking a closer look at the underlying assumptions can sometimes open up new possibilities. But, says Nussbaum: "In one way Hegel's approach to tragedy is too simple. For it ignores the possibility that some degree of tragedy is a structural feature of human life" (p. 1013). A trace of tragedy may always remain.

[...] the residuum of tragedy at the heart of human life. Some rich and complicated aspects of life just are likely to be in tension with some other rich and complicated aspects,

and even the wisest Hegelian will not be able to remove the possibility of tragedy [...]. (pp. 1035/1036)

We should be aware of the limitations of looking for a way out of the dilemma through the search for a middle ground. Sometimes, harm cannot be resolved or reduced, and this needs attention in MCD.

Finally, formulating harm in MCD can help to repair harm. We encounter the notion of 'moral repair' in various contexts: in literature on combat trauma (Litz et al., 2009), on sexual abuse (Ward & Moreton, 2008) and on moral distress among nurses (Peter & Liaschenko, 2013). This latter article states that 'counterstories' are important in repairing the moral identities of nurses. Telling stories of reliability and nursing expertise are important in order to counterbalance the narrative of nurses as subordinates. Analogously, the narrative element in MCD is important in order to impart strength to one another when dealing with harm. This narrative element is experienced in MCD through the discussion of harm, through the retelling of the case and the joint discussion of the underlying values. Exactly how this narrative element of MCD serves to increase resilience requires further research.

The word 'repair' might give the false impression that everything can in the end be controlled in healthcare. As the results show, repair can only be partial; residual harm remains, and not all harm can be repaired. There is sometimes long-term lasting harm that patients must learn to live with, and for which health professionals to a certain extent feel responsible.

## Conclusion

This study showed that addressing harm in moral case deliberation in tragic situations offers an important moral learning opportunity for participants and others involved. Discussing harm reveals what is at stake, and makes visible that tragic decisions have lasting effects. Discussing harm helps to repair negative consequences of decisions where possible. Yet, harm cannot be fully undone.

For health professionals, the added value of addressing harm in MCD lies in the awareness of tragic situations. Through the discussion of harm, MCD contributes to increased sharing, supporting and understanding one another in tragic situations. Also, offering comfort and acknowledgement, and contributing to the resilience of professionals in the difficult decisions they face are benefits of discussing harm in MCD.

#### Abbreviations

CES: Clinical ethics support; MCD: Moral case deliberation; NICU: Neonatal intensive care unit

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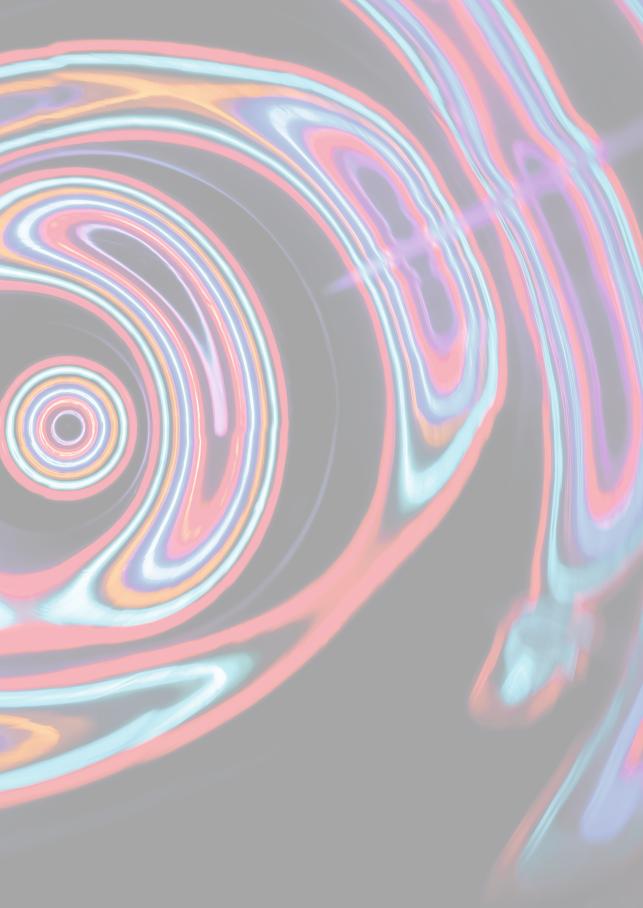
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# The role of emotions in moral case deliberation: visions and experiences of facilitators

Keywords: Moral Case Deliberation | clinical ethics support | emotion | tragedy

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# Abstract

Moral Case Deliberation is intended to assist healthcare professionals faced with difficult dilemmas in their work. These are situations that involve emotions. During Moral Case Deliberation, participants are invited to reflect on moral views and deliberate on them. Emotions are not explicitly addressed. This article aims to elucidate the role of emotions in Moral Case Deliberation, by analysing experiences of Moral Case Deliberation facilitators. Our research shows the role of emotions varies according to the phase of the Moral Case Deliberation process. One negative aspect of emotions is that they can obstruct the Moral Case Deliberation discussion or distract from the moral question. A positive aspect is that they bring the dilemma into sharper focus. Devoting attention to emotions can help to ensure that responsible decisions are made, while also increasing the moral resilience of participants.

# Introduction

Moral case deliberation (MCD) is a form of Clinical Ethics Support (CES), intended to assist healthcare professionals faced with difficult dilemmas in their work. Should you continue to treat a young patient to give him hope when there is no realistic chance of improvement? Suppose a pregnant woman is diagnosed with cancer. Should you proceed with chemotherapy in the knowledge that it may harm the unborn child? Difficult dilemmas such as this often involve a 'tragic situation', a term used when every available option has negative consequences and it is therefore impossible to make a straightforward, 'right' decision. In most cases, this is accompanied by intense sadness and grief, a need to accept the inevitable, a feeling of being powerless, and a threat to human dignity (Spronk et al., 2017). What is the significance of emotions evoked by tragic situations within Moral Case Deliberation? Do emotions preclude open, fruitful discussion? Are emotions indicators of our own values, concerns, beliefs and priorities? How do they impact the role of the facilitator, and how should he or she incorporate emotions into the process?

In this study, we are concerned with the experiences of MCD facilitators with regard to emotions. We examine three key questions: What is the role of emotions? What are the negative and positive implications of emotions? How do facilitators react to participants' emotions?

Every MCD process is led by a trained facilitator, whose practical experience of the technique forms a valuable source of knowledge and expertise. In order to gain an accurate impression of the role of emotions in MCD, we have therefore chosen to focus on the visions and experiences of facilitators. Facilitators have an overview of the process of MCD and the emotions that are expressed by all participants during MCD. We are also interested in how facilitators make use of these emotions during MCD's.

We begin by defining the concepts of emotion and Moral Case Deliberation based on the literature. The article then goes on to describe the research methodology applied and the results obtained, followed by the authors' reflections and conclusions as shown in Table 1.

What is the role of emotions?		
During the initial phase	Signs of having been 'moved'	
During the reflection phase	Realization of values and concerns	
	Expression of responsibility	
During the concluding phase	Expression of relief and gratitude	
What are the negative and positive a	aspects of emotions?	
Negative aspects	Emotions obstruct MCD	
	Emotions distract form the moral question	
Positive aspects	Emotions bring the ethical dilemma into sharper focus	
	Emotions as source of new insights	
How does the facilitator respond to	emotions?	
Devoting attention to emotions	Providing time and space for emotions	
	Acknowledging emotions	
	Avoiding psychologization	
Limiting negative aspects of	'Parking' emotions	
emotions	Encouraging participants to distance themselves from	
	emotions	
Exploiting positive aspects of	Making emotions explicit to support the MCD process	
emotions		

Table 1. Summary of the key elements of emotions in MCD

## Emotions

Emotions have been subject to considerable research (Damasio, 1999; Frijda, 2005; Frijda, 2016). Damasio describes emotions as a physical response to a significant stimulus (1999, p.51). That stimulus triggers an unconscious neurological reaction in the brain, which we can observe from someone's external appearance or demeanour. Emotions have a biological function as a form of survival mechanism (p.53). At this primary level, emotions are a physical marker of what we consider important. The basic emotions are happiness, sadness, fear, anger, surprise and disgust (p.50). There are also 'social emotions', such as embarrassment or guilt, and 'background emotions', such as calm or tension, which Damasio describes as 'affective states that constitute the tacit backdrop of experience' (p.51).

Other authors have zoomed in on the more reflected aspect of emotions (which Damasio terms 'feelings'(p.37)). Frijda notes that emotions reveal "what the organism cares about: his, her or its concerns, in dealing with the world and itself" (2016, p. 618). Thus, emotions show what we consider to be important and where our intentions lie. They demonstrate our willingness and desire to take action. Frijda also states that emotions can be 'pointers' to the underlying sources from which they derive. If we take note of our emotions at a given moment, we may be able to trace that source and understand why we feel that way. This process of reflection gives rise to new motivation and new knowledge (2005, p. 490). Talking openly about emotions is also important, Frijda contends. "Emotion sharing forms one of the building blocks of intimate human relationships" (2005, p. 492).

Martha Nussbaum, who has studied emotions from the philosopher's perspective, states that:

Emotions [...] involve judgements about important things, judgements in which, appraising an external object as salient for our own well-being, we acknowledge our own neediness and incompleteness before parts of the world that we do not fully control. (2001, p.19)

In her vision, emotions relate directly to a particular objective or intention. Emotions are an expression or manifestation of what a person considers important. As such, they are closely allied to values. People show who they are through the things that move them. Emotions thus form an important starting point for ethical reflection (2001). By consciously observing and examining emotional responses, facilitators can assess their value and significance to the discussion.

#### Moral case deliberation

Moral case deliberation (MCD) is a structured method for investigating a moral issue. It is undertaken

in a group setting, guided by a trained facilitator. MCD participants are often healthcare professionals (doctors, nurses, paramedics), but might also include managers, family members or even patients themselves. The principal element is a case presented by one of the participants. This case must involve a concrete, personal experience from the past or present, not a hypothetical situation (Stolper et al., 2016).

The main aim of MCD is not to arrive at a solution, but to explore the ethical question at hand and thus encourage critical reflection on the values associated with the facts of the case (Stolper et al. 2016). This reflection is brought about by dialogue. Dialogue involves the exchange of various perspectives in order to arrive at a 'fusion of horizons' among the participants (Gadamer, 1060). The underlying purpose is to search for common ground between one's own and others' experiential horizons, in order to understand one another better and develop a richer, more complete understanding of the situation.

To structure the dialogue, the facilitator uses a specific conversation method. Several such methods have been developed (Van Dartel & Molewijk, 2014). A familiar option is the 'dilemma method' in which a key step is the analysis of the case in terms of perspectives, values and norms (Molewijk & Ahlzen, 2011; Stolper et al. 2016). It is customary to produce a chart or table listing the perspectives of all persons involved in the case, known as the 'stakeholders'. The participants in the MCD session seek to identify the values which underpin those perspectives, the norms which serve to concretize the values, and possible courses of action. The norms and values concerned are the personal visions of the stakeholders. Other deliberation methods also explicitly address values.

Values express what is important for participants. In this sense, they resemble emotions. Yet, in MCD, participants are not invited to share emotions, but to reflect on moral views and deliberate on them. Emotions are not explicitly addressed in MCD. This raises the question what role emotions play in MCD. Are emotions implicitly present in the way in which participants talk about values? Can making explicit the emotional aspects of moral values and concerns play a role in the process of moral deliberation? This article aims to elucidate the role of emotions in MCD, by analysing experiences of MCD facilitators.

# **Research methodology**

# **Data collection**

This study forms part of a larger research project examining the relationship between MCD and tragic situations. In healthcare practice, care providers can be confronted by a tragic situation in which they must make decisions that will have far-reaching consequences. To what extent can MCD help them make those decisions? We investigate the role of MCD in dealing with tragic situations by looking at harm (Spronk et al., 2020) and worldview. This article focuses on emotions.

Semi-structured interviews were held by the first author with a number of MCD facilitators who were asked to give examples of MCD sessions they had conducted and to briefly explain the process and outcomes. Facilitators using the dilemma method were asked about the role of emotion. Respondents who do not use the dilemma method were asked whether the aspect of emotion is incorporated into their favoured approach and, if so, how.

The following criteria were used to select respondents:

- A minimum of one year's experience in MCD facilitation.
- Currently working in healthcare (hospital or psychiatric clinic).
- Representative distribution in terms of gender, age, professional background and field of operation.

Twelve facilitators were interviewed (six male and six female) at their workplace or at their home. A procedure of purposive selection was followed. As the respondents were known for their experience in MCD, they were asked to participate. No one refused. The respondents included two clinical ethicists, three spiritual counsellors, three medical specialists, one paramedic, two healthcare managers, and one nurse manager, thus spanning a wide range of educational backgrounds. The respondents have acted as facilitators with various groups. Six worked in hospitals, three in mental healthcare, and three in both. The age of the respondents ranged between 30 and 68 years. The facilitators used a range of MCD methods: eight used the dilemma method, next to other methods, four only used other methods. These methods entail value clarification

and the Socratic dialogue. Although these methods are similar in reflecting on an ethical case, they do not take the ethical dilemma as a starting point for the deliberation.

We included facilitators with different methods to have a broad spectrum. Since moral issues are accompanied by emotions, this entails a challenge for any facilitator of MCD. Because this is our primary focus, we won't be looking at differences between the methods facilitators use.

With the respondents' consent, all interviews were recorded, transcribed and anonymized by the first author and an assistant. Amsterdam UMC, VUmc location's Medical Research Ethics Committee determined that the study does not fall under the requirements of the Medical Research with Human Subjects Act (WMO) as no actual interventions were performed.

#### Data analysis

The researchers aimed to identify the key elements concerning emotions in MCD, based on facilitators' personal experiences. Those experiences were defined as broadly and openly as possible using the Grounded Theory approach as developed by Charmaz (2006).

Data analysis was carried out in three stages. The first stage involved open coding: the first two interviews were coded independently by two researchers and the results compared in order to establish inter-rater reliability. The results were discussed by all three authors. Based on this process, the topic list for the next interviews was refined. The next two interviews were coded by the first author, after which the three authors reflected on the resulting coding tree, in order to foster validity. The first researcher then conducted another eight interviews, two of which were also co-coded by a research assistant to again establish inter-rater reliability.

During the second stage, focused coding, eight interviews were analysed, and codes were clustered into overlapping themes. The results were discussed by the first two researchers deciding on the best phrasing of the themes. This produced 14 over-arching themes. The codes of actions of facilitators were formulated as gerunds or participles (verbs ending in '-ing') in accordance with Tweed and Charmaz (Charmaz 2006; Tweed & Charmaz, 2012). Gerundbased coding ensures a focus on actions rather than concepts, retaining a closer connection to the data (e.g. 'providing time and space' rather than just 'time and space'). This approach suited our study since we sought to investigate how emotions are actually addressed in MCD practice.

The third phase, axial coding, examined the relationships among and patterns between the various themes, after which the over-arching themes were refined and the final categories formulated. After the full analysis of eight interviews, theoretical saturation

#### Chapter 4

was reached. We analysed the other four interviews, with participants from various backgrounds. In the analysis no new themes were found.

# Results

The section below describes the categories and themes identified. The table is based on the interview analysis. The key elements of emotions respondents address, derive from multiple MCD's referred to by the respondents. Examples of cases discussed in these MCD's are forced treatment versus private integrity, the request of relatives to continue treatment versus the professional account that prolonging treatment is medically useless and adds suffering (and vice versa), stopping or continuing treatment in the neonatology ward and rights of potential parents versus the rights of the child in fertility treatment.

# What is the role of emotions in Moral Case Deliberation?

Results show that all facilitators have to deal with emotions, regardless the method they use. All facilitators had similar experiences. The way of dealing with emotions was not determined by the method used. Our findings are more general in nature. The role of emotions varies according to the phase of the MCD process. In the initial phase, emotions reveal what is important to the participants and what they consider to be at stake. During the reflection phase, emotions indicate fundamental values and concerns. In the concluding phase, emotions reveal what MCD has achieved.

# Emotions during the initial phase

**Signs of having been 'moved'**. In the earliest phase of MCD, emotions can show that the participants have been moved and affected by the situation under discussion. This may be apparent when participants react with annoyance or indignation, perhaps in response to situations in which avoidable mistakes have been made or which have otherwise caused frustration.

This patient and his family decided to try alternative therapy. (–) That didn't work, so they ended up back here. (–) She (the doctor) was actually very annoyed with the man. 'You come back to me now? It's too late. There is really nothing more I can do.' (Interview 11)

(-) People sometimes raise their voice. They say that the daughter shouldn't be allowed to make this kind of decision. It can help to say, what's this I see? Yes – irritation or anger. I find it very important to state what it is. And I also find it important that people acknowledge that what they are feeling is all tied up with how they view their profession. (Interview 6)

Being moved can also express itself as sadness or grief.

(-) There was a case involving a young man who just didn't want to carry on. He wanted to stop treatment there and then, even though from a medical perspective there was still some hope of improvement. He had just given up. His doctor had built a close professional relationship with this young man, aged just 17. The doctor therefore had tears in his eyes when he heard his decision. (Interview 5)

One facilitator reported that he expressly enquired about emotions during the case presentation, and was particularly interested to hear about any feelings of sadness.

Once the case has been presented, I always ask the participants, 'How has this affected you? What do you feel about it? Then I probe further, asking which of the four basic emotions is at play. Are you angry, afraid, happy, sad? The answer is rarely 'happy'. Sometimes it is 'afraid', while 'angry' is a common response. But I keep on asking until hopefully someone says 'sad'. In a real moral case, or a moral dilemma that has arisen from the tragedy of reality, there will always be a layer of sadness and sorrow. (Interview 4)

Besides anger or sadness, shock can also be cited as an emotion. In some cases, this sense of shock can persist for some time.

But that was a case that stayed with me, as facilitator, for several days. I kept thinking, 'what a horror that must be, not only for the two doctors involved but also for the young man and his family. Dreadful – just dreadful.' (Interview 12)

#### Emotions during the reflection phase

**Values and concerns.** The emotions that emerge during the reflection phase can be indicators of deep-seated values an concerns.

I think that this may also provide input for the selection of values. It can be a way of identifying certain values within yourself more quickly. As I see it, your emotional engagement and involvement may be based on some underlying value which is under threat. (-) In this case, the helplessness of the young man was extremely clear, having been so well described by the person presenting the case. So that appeals to your desire to help, but also to your feelings of justice when it comes to the imbalance of power. (Interview 12)

**Expressions of responsibility.** If a choice has to be made during the MCD process, emotions may reveal that the participants do feel real responsibility for deciding what they consider morally appropriate, and that they are aware of exactly what is at stake.

At the same time, especially if the choice involves finding the lesser of two evils, making the decision can be a source of great tension. It means that you are taking real responsibility. (-) This is when Moral Case Deliberation can be very useful. It makes

participants more comfortable with their responsibility, and more secure in making the choice required of them. (Interview 6)

## Emotions in the concluding phase

**An expression of relief and gratitude.** Several respondents report that a common emotion during the concluding phase of MCD is that of relief.

I can see the relief! (-) You see it on everyone's face. They have reached the end. At the outset, these same people might have said, 'no – I don't have time, think of the rosters and the crisis and whatever'. But now they say, 'We must do this more often. We should make more time available for it.' (Interview 5)

I think that the greatest contribution to good care is the acknowledgement of the tragic element. The relief is catharsis; the process has provided consolation. People feel a desire to share with each other, to discuss their thoughts. That is good. Although it is a rational process, perhaps the greatest benefits are at the emotional level. (Interview 4)

That relief is an important emotion is also evident form situations in which it is absent.

I watch faces very carefully during a Moral Case Deliberation discussion. You often see a sort of relief on someone's face. They suddenly seem more relaxed because they have shared the burden of their concerns, or perhaps it is because they now know what they must do and why, and that feels good. But on this occasion, there were no signs of relief. Everyone continued to look very sullen. (Interview 1)

Another emotion reported by respondents at the conclusion of the MCD process is gratitude. The discussion of what they consider to be important and of value has resulted in a reappraisal of the tragic situation, and this often engenders gratitude for the participants' respective contributions. Thorough assessment of what the participants can and should do for the patient is not only a process of ethical reflection but also one which enhances knowledge and crystallizes standpoints.

That was also the conclusion yesterday. The word 'tragic' was abandoned. In its place came gratitude that we were able to do this again. (Interview 11)

My input is limited, but by facilitating MCD and allowing everyone to contribute, I could ensure that the physiotherapist's perspective was also heard. (-) That was a turning point. The team agreed that it had been an extremely useful session. (Interview 11)

# What are the negative and positive aspects of emotions?

The interviews confirm that there are both negative and positive aspects of emotions within the MCD process.

#### Negative aspects

**Emotions can obstruct MCD.** Respondents report that emotions can obstruct MCD by clouding the thinking processes of the participants.

MCD is often so effective because the diversity of opinions and perspectives forces you to approach a problem from several different angles. However, this becomes impossible if you are bogged down in a particular emotion. You are so overwhelmed by, say, sadness that you see no alternative ways of looking at the situation. It's a question of, 'I hear what you're saying but that just cannot be right.' (Interview 5)

Ethics can be seen as an exercise in thinking. When you're dealing with a tragic situation, it is difficult to think clearly about all the aspects involved. Why? Because you are so deeply affected by your emotions that you cannot distance yourself from those emotions. (Interview 7)

If emotions become too intense, it may be appropriate to consider another form of discussion as an adjunct.

Something I learned from that is that if people are so tied up in their emotions, it is probably better to have a different type of conversation, or a different conversation altogether. If you become aware of intense emotions at the very earliest stage, it may be that MCD is not the appropriate approach after all. We then have to seek some alternative to support the same aims. (Interview 5)

**Emotions distract from the moral question.** Respondents suggest that emotions can distract from the moral question, or may be difficult to reconcile with that question.

The doctors who were deliberating this case, disconcerted by the outcome, began to cite the existing protocol. 'Hang on – have you thought of this, have you considered that?' As a result, the discussion was not so much led by moral considerations but by what the protocol dictated. (Interview 12)

We're taking part in a Moral Case Deliberation, so I expect a moral question. If you want to talk about your emotions, fine – we'll do that. But then it's not really a moral deliberation. (Interview 4)

### Positive aspects

**Emotions bring the ethical dilemma into sharper focus.** Respondents report that emotions can reveal precisely where the ethical dilemma lies, and can bring it into sharper focus.

I often find myself asking 'and how do you feel about that?' or words to that effect. (-) In the practice of healthcare, what you feel can often point you in the right direction, or at least point you in the direction of where the ethical dilemmas lie. (Interview 6)

This is important because it reveals precisely why you feel so involved, and also reveals which ethical principle is lacking. If people become angry or annoyed, it is always because they perceive an injustice. That is the only explanation. You're angry – why are you angry? (Interview 7)

**Emotions as a source of new insights.** Emotions can be a source of new insights, and as such it is important that they are explored. Emotions can also help to identify and crystallize personal values.

But I also consider emotions extremely important as the fountainhead of new knowledge. I am therefore inclined to assign a clear role to emotions, and to actively explore that role. (-) It becomes possible to identify the values that are at stake in a way that would not be possible when applying rational thought. (Interview 12)

## How does the facilitator make us of emotions?

When asked how facilitators respond to emotions and use them to further the discussion, respondents report that they devote conscious attention to emotions, attempting to mitigate their negative aspects while fostering the positive aspects.

#### Devoting attention to emotions

**Providing time and space.** Respondents state that it is important to provide time and space for emotions. This supports emotional processing and increases participants' understanding of each other.

MCD offers participants a firm footing from which to move on, an opportunity to express their concerns, and a chance to reflect on matters together, whereupon the situation becomes much clearer for all concerned. I think there is also some 'emotional processing' involved. That may sound rather lofty, but perhaps the MCD session is the ideal opportunity to make time and space available for emotional processing. (Interview 3)

We once held an MCD about how we deal with everything that we encounter during our work. Yes, there was room for sadness and anger, which was appropriate because it allowed us to see how the issues affect everyone in the department. We could then understand each other far better, which I thought was a good outcome. So yes, I think there should be time and space for emotions. (Interview 10)

**Acknowledging emotions.** Respondents state that they consider it important to acknowledge emotions during the MCD process.

I often ask, 'how does that make you feel?' Having been told, I do not necessarily reply that 'what you are feeling is good', but it is important to acknowledge that a situation has evoked some emotional response. (Interview 6)

Acknowledging emotions helps to foster mutual connection and consolation.

I have noticed that when participants find certain statements to be relatable, they provide verbal confirmation, which is a good form of support. People might share their pain, or tell each other about their crises of conscience. When these accounts are acknowledged by the group, I sense the relief and I see connections becoming stronger. Everyone seems to be thinking, 'Well, I'm glad I'm not the only one'. (Interview 12)

It can be a great consolation when others acknowledge that, while we can do so much and can talk at length about various issues, there are certain things that we cannot do. We can never take away the sadness and sorrow of parents who have been denied a healthy child, for example. There is absolutely nothing we can do. (Interview 1)

**Avoiding psychologization.** The respondents state that the attention devoted to emotions should focus on exposing the participants' underlying motivation. It should not be a process of psychologization, but one designed to gain an understanding of moral experiences, values and concerns.

As an ethicist, I do not wish to psychologize. I want to concentrate on what motivates people, I want to understand their values. I am not interested in how their motives and values affect them, or what significance they attach to them. (-)(Interview 1)

I can only tell you what I do with emotions, which is to merely enquire about them. I regularly ask, 'what feelings does this create for us? Is there anyone who would like to say something about this.' I may notice that someone appears distracted, in which case I will ask them to tell the group what they are thinking about, what is going through their minds. I could also notice that someone is becoming irritated. So yes, I do devote very close attention to emotions but not in the pastoral sense of 'How are you feeling? Why do you feel like that?' I am more alert to signals that tell me whether we are on the right track. (Interview 6)

#### Limiting the negative role of emotions

**'Parking' emotions.** Respondents report that emotions are sometimes 'parked' in order to expedite the MCD process. This means that some attention is devoted to the emotions but they are then set aside. The discussion may or may not return to them later.

Personal aspects can play a very prominent role in the 'emotional round'. Someone may say, 'I am also a mother...I have a child of 17.' This is clearly likely to influence the participant's subsequent contribution to the discussion and how it is received. We

therefore attempt to 'park' such considerations and focus exclusively on her professional role and responsibilities. (Interview 4)

I do believe there must be a 'flow'. The deliberation cannot be allowed to stall. It is good to devote some attention to personal emotions, but not for too long. I am inclined to 'park' these emotional aspects and return to them later. I say something to the effect of, 'I hear what you're saying and I am mindful of how this affects you, but let's come back to it later.' (Interview 8)

**Encouraging participants to distance themselves from their emotions.** Respondents stress the importance of encouraging participants to distance themselves from their emotions in order to facilitate thorough reflection.

Obviously, you can only take a stance with regard to emotions once you are able to establish a certain distance from those emotions. If you constantly lapse into sadness or anger, you are in fact being dragged along by the emotion. The emotion is too strong, too dominant. In that case, it will be very difficult to reflect on it. (Interview 7)

Respondents report that they can keep emotions in check by adopting a reflective attitude during the MCD session.

By expressly stating the appropriate attitude for Moral Case Deliberation, [...] you prompt participants to adopt a contemplative, diagnostic approach. [...] This does not make emotional responses impossible but it does serve to temper them. (Interview 12)

Where emotions are particularly strong, it may be necessary to isolate them to mitigate their effect.

It helps. It can sometimes be worthwhile to draw people out of their emotional state. Perhaps they have a patient who is particularly difficult. They become very emotional and 'wound up'. You encourage them to see things from the patient's perspective. The annoyance, frustration and feeling of being powerless can then melt away, to be replaced by a certain empathy and sensitivity towards the patient. I find it very valuable – being able to temper emotions like this. (Interview 5)

# Exploiting the positive aspects of emotions

**Identifying emotions to support the MCD process.** Respondents state that they find it important to draw attention to the emotions they observe during the MCD process and to make them explicit. They state what they have seen and probe further, doing so in an open manner whereby participants are asked whether they would care to say anything about their emotions. Identifying and expressly recognizing emotions helps to exploit their positive aspects.

If I observe emotions at play, I always say so. I may see that a particular aspect of the discussion elicits certain emotions in one or more participants. It can be difficult but I always say what I see. In this respect, I do indeed devote attention to emotions. (R5) If you ask me, and when I reflect upon it, I think it is part of the facilitator's role to enquire about emotions. I might say, 'oh ... can I just ask if there is anyone who would like to say something about this. I get the impression that ... Am I right?' (Interview 12)

When identifying and clarifying emotions, attention is also devoted to their physical manifestations.

When I talk about 'feeling' something, I try to let people really feel something in a physical sense. I ask them whereabouts in their body they are feeling it. Is it a sort of unconscious, subliminal feeling, or is it a real physical sensation? This is something I try to teach people to be aware of. As a care provider, your body is an instrument which can provide useful indicators. (Interview 6)

Encouraging the open discussion of emotions during the MCD process helps participants to become more resilient.

I think it is fine that people can feel, say, powerless, but at the same time it is very important that they have the motivation needed to get back to work tomorrow. Even where the outcome is certain and there is no choice, you still have to make certain decisions, particularly in tragic situations. It is useful to think about this during the MCD session. (Interview 6)

We have to remain professional, but in reality everyone has feelings of sadness or grief when confronted by various situations. It was good that this became so apparent during the sessions. It gives one strength to carry on together because you have had the opportunity to discuss these feelings. You feel reinvigorated – we are all in this together, that sort of thing. (Interview 10)

# Discussion

This study is concerned with the experiences of MCD facilitators with regard to emotions. What is the role of emotions, what are the negative and positive aspects of emotions, and how do facilitators react to emotions?

The role of emotions varies according to the phase of the MCD process. In the initial phase, emotions are evidence that the participants have been affected by the case under discussion. Emotions such as anger, sadness and shock are appropriate responses to a

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moral dilemma. They are pertinent to the very difficult issues which the participants are expected to deal with.

During the subsequent reflection phase, emotions are an indicator of the participants' moral values and concerns. They form useful points of departure for further in-depth contemplation. Emotions are also a manifestation of the sense of responsibility felt by the participants. They are indicators of what participants consider to be the germane aspects of the moral dilemma under consideration, both in practical terms and with regard to the values at play.

During the concluding phase, emotions can reveal what participants have achieved through the MCD process. They may, for example, show relief or gratitude. The operative word here is 'may': these emotions are not always evident. If there is no sense of relief, has the MCD process failed? Not necessarily. Relief is a complex emotion, particularly when dealing with a tragic situation. MCD helps participants to 'share the load' with each other (Spronk et al., 2017) and also helps to identify the important aspects of the moral dilemma. However, the tragic situation remains no less tragic and it is important to acknowledge this.

That emotions have different roles in the various phases of the MCD process is borne out by Svantesson et al. (2018). In this study, a distinction was drawn between the restorative and normative functions of emotions in MCD. The 'restorative' function refers to the restoration of the participants' sense of wellbeing, achieved through being able to express and discuss the emotions involved in their work, such as the frustration caused by a patient's behaviour or that of angry relatives. The 'normative' function refers to the appropriate course of conduct. What is the 'right' thing to do? Svantesson et al. state that it is important to devote due attention to the restorative function of emotions because this provides emotional support and the relief of moral distress. However, if too much attention is given to the restorative function, this will distract from the moral question. This finding is in line with an article by Leget about training for medical students (2004). If students become emotionally involved in an issue, the author states, this does not automatically give rise to a discussion at the ethical level (2004, p. 490). Additional steps are needed to prompt such a discussion. Leget goes on to note the importance of actively demonstrating the correlation between values and principles on the one hand, and the emotional response on the other. It is useful to enquire into the implicit moral content of a person's emotions, and it is important to engage in a joint exploration of the connection between emotion and 'the good life' (p. 493).

We note that facilitators distinguish between the negative and positive aspects of emotions. One negative aspect is that emotions can hamper the discussion, or can distract from the moral question. If emotions obstruct MCD, it may be necessary for the facilitator to halt the discussion and initiate a 'meta-conversation', i.e. 'a conversation about the conversation during the Moral Case Deliberation. This may be relevant when one of the participants is deeply affected, sad, or in confusion, and needs a break' (Molewijk et al., 2011, p. 388). The positive aspects of emotions are that they can bring the dilemma into sharper focus and that they can provide a source of new insights. This is in line with assertions made by Damasio, Frijda and Nussbaum. Emotions show us what we consider to be important; they reveal the fundamental values which are important to the process of moral reflection, and they 'highlight values that help to steer the course of action to be taken' (Spronk et al., 2017). Facilitators state that it is important to devote attention to emotions, and to acknowledge those emotions. By taking time for emotions, MCD helps to foster mutual understanding and aids in the emotional processing of the situations faced by care providers. Respondents note that there is a difference between ethics and psychology. MCD is not a counselling or peer group session which sets out to help one specific individual. MCD is an exploration of what each participant would have done had they been in the position of the person who contributes the case for discussion (Molewijk et al. 2011). In MCD, the focus is not on emotions as such, but rather on ethical reflection. Mitzcherlich and Reiter-Theil discuss the difference between ethics consultation and psychological supervision (2017). The methodology of ethics consultation, the authors contend, is structured and rational. It permits some consideration of emotional aspects. Psychological supervision, by contrast, is process-oriented and very much geared to the emotions of the participants. A facilitator must have the skills required to deal with emotions that are likely to disrupt the process, and if necessary to refer the case to psychological supervision.

Facilitators attempt to restrict the negative aspects by 'parking' emotions and encouraging participants to distance themselves from their emotions. They attempt to exploit the positive aspects of emotions by identifying and drawing attention to emotional responses, and by encouraging their open discussion. Our respondents suggest that this helps to increase participants' resilience. Resilience serves to protect against moral distress (Rushton & Faan, 2017; Traudt et al., 2016). Traudt et al. stress the importance of 'moral imagination' – the ability to apply others' values to a situation – and the 'moral community', in which all members are involved in the decision-making process (2016). This is in line with the facilitators' experience. They note that identifying and openly discussing emotions helps participants to place themselves in other's position, seeing matters from different perspectives, and encourages them to make and implement moral decisions together as a joint process.

# Conclusion

The discussion of a moral dilemma using the MCD approach will inevitably involve emotions. The role of emotions varies according to the phase of the MCD process. In the initial phase, emotions are an indicator of the participants' sense of involvement in the situation: the degree to which they have been moved or affected. During the reflection phase, emotions can reveal the fundamental values and concerns of the participants, becoming an expression of their perceived responsibility. In the concluding phase, the emotions displayed may be those of relief and gratitude. One negative aspect of emotions is that they can obstruct the MCD discussion or distract from the moral question. A positive aspect is that they bring the dilemma into sharper focus. Emotions can also be a source of new insights. Facilitators believe that their role involves devoting due attention to emotions, limiting their negative impact and exploiting the positive aspects. Their main focus is not on emotions as such, but rather the reflection on the ethical aspects of the situation under discussion. This can help to ensure that responsible decisions are made, while also increasing the moral resilience of the participants.

## Ethics approval and consent to participate

The respondents gave their approval and consent to participate. Respondents are indicated by number instead of by name or function. All names, places and other characteristics of the participants involved are changed and therefore untraceable. The Amsterdam UMC, VUmc location's Medical Research Ethics Committee declared the study did not fall under the Medical Research (with Human Subjects) Act (WMO), as no interventions were performed.

## **Consent for publication**

The respondents gave their approval for publication.

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# Availability of data and material

The dataset that supports the conclusion of the article is available in Dutch.

# Authors' contributions

BS contributed to the conception of the study and participated in its design, development and coordination, and was involved in drafting and revising the manuscript. GW contributed to the conception and participated in the design and development of the study and was involved in drafting and revising the manuscript. HA contributed to the conception and participated in the design of the study and was involved in drafting and revising the manuscript. All authors read and approved the final manuscript.

# **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

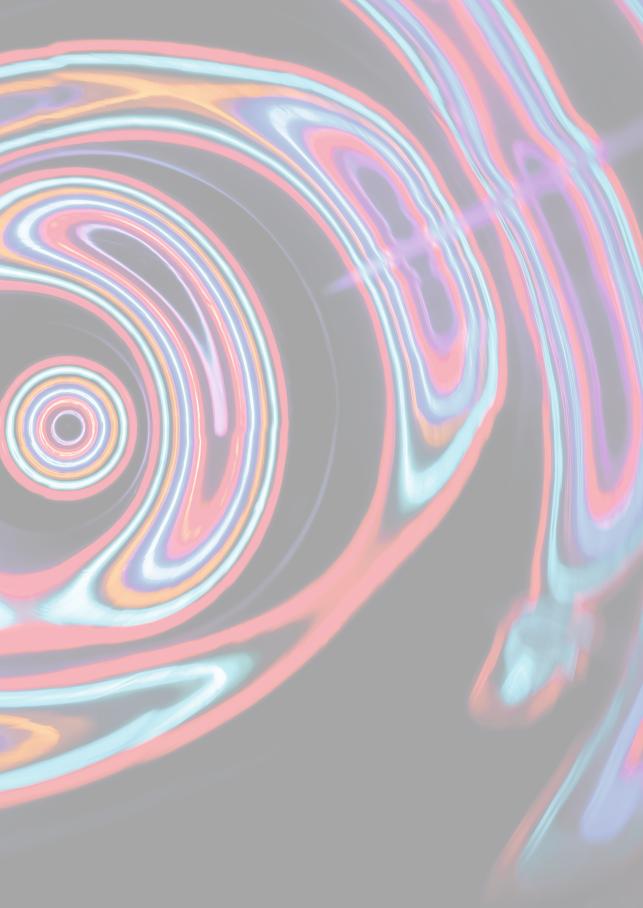
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# 5. The role of worldview in moral case deliberation: visions and experiences of group facilitators

**Keywords:** Moral case deliberation | Clinical ethics support | Worldview | Religion | Spirituality | Values

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# Abstract

This study investigates the role of worldview in moral case deliberation (MCD). MCD is a form of clinical ethics support which aims to assist caregivers in refection on moral dilemmas, experienced in daily practice. Bioethicists acknowledge that existential and religious aspects must be taken into account in the analysis of ethical questions, but it remains unclear how these elements are addressed in clinical ethics support. We investigated how facilitators of MCD address worldview in MCD. MCD facilitation is often done by spiritual caregivers, but not in their role as spiritual caregiver. Discussing worldview is no standard part of the procedure in MCD. This study was qualitative, focusing on the views and experiences of the facilitators of MCD. Semi-structured interviews (N=12) were conducted with facilitators of MCD. Grounded theory was used for analysis. The results show that worldview plays both an explicit and an implicit role in the MCD process. The explicit role concerns the religious beliefs of patients and professionals. This calls for avoiding stereotyping and devoting attention to different visions. The implicit role comes to the fore in addressing core values and spiritual fulfillment. In order to clarify the fundamental nature of values, more explicit attention for worldview might be useful during MCD. However, this should be done with caution as the term 'worldview' might be interpreted by participants in terms of religious and personal beliefs, rather than as an invitation to reflect on one's view of the good life as a whole.

# Introduction

Care professionals frequently face difficult dilemmas. Do you agree to terminate a pregnancy at the parents' request if the baby will be born with a disability? Should you tell a patient that his condition is terminal if the family has asked you not to? Dilemmas like these involve perceptions of the value of life and the individual's worldview. "Worldview refers to fundamental beliefs about life, death and suffering that structure people's ideas on how life events are related" (Littooij et al., 2016a, p.7). "Worldview is part of 'global meaning', a basic set of beliefs and goals that guide the way in which people give meaning to their lives" (Littooij et al., 2016a, b; Park, 2013a, b, p. 358.). It concerns questions which touch upon the fundamentals of our existence, defining who we are and where we seek to belong (Aerts et al., 2007, p. 5; Alma, 2018, p. 45; Plante & McCreadie, 2019, p. 321; Taves et al., 2018). Moral case deliberation is about reflecting on making professional choices and treatment decisions. Refection on underlying values and norms is important in order to be able to make responsible choices. This refection takes place in moral case deliberation. Values and norms can be formed by belief systems and are determined by the meanings people give and visions they have on life, death and suffering. That is the reason we opted to define worldview as part of global meaning. Bioethicists acknowledge the importance of worldview in clinical ethics support, both in a general sense (Kørup et al., 2018; Mustafa, 2014; Turner, 2003; White et al., 2018) and in specific areas (Bandini et al., 2017; Mathieu, 2016; Mohamed & Noor, 2014). They emphasize that existential and religious aspects must be taken into account in the analysis of ethical questions in clinical practice. The existing literature tends to focus on identifying and defining the various elements of worldview. It remains unclear how these elements are, or should be, addressed by those involved in clinical ethics support.

Moral case deliberation (MCD) has been developed as a component of clinical ethics to help care providers make morally conscionable choices. An MCD session explores an ethical issue described by one of the participants and drawn from his or her personal experience. The deliberation is structured by a specific method and is led by an experienced facilitator (Stolper et al., 2016). MCD facilitation is often done by spiritual caregivers, but not in their role as spiritual caregiver. Reflection on ethics can be part of spiritual care. Facilitating MCD, however, requires specific skills and knowledge of methodologies. Many spiritual caregivers are interested in MCD and are trained as facilitator. However, not every spiritual caregiver is a trained facilitator. In their role as facilitator, they are trained to address values, but not worldview, as this is no standard part of the procedure in MCD. The MCD session generally takes place within the clinical department concerned. It is attended by departmental staff and representatives of other disciplines involved in the case under discussion.

In this article, we examine how MCD facilitators approach worldview as a component of clinical ethics. Facilitators are a source of experience and knowledge, how worldview

is addressed in MCD. Our choice was to rely on their experiences. In essence, MCD entails reflection on the right thing to do. It, therefore, considers the perspectives of all persons involved in the situation and explores their personal norms and values. The investigation of these values can be accompanied by a reflection on existential aspects. What importance do MCD facilitators attach to such existential aspects? How do they use them to enhance the deliberation?

Our first research question is therefore: What is the role of worldview in MCD? The second research question is: How do MCD facilitators act in response to worldviews?

We begin with a brief overview of MCD based on the literature, followed by a description of our research method and results. This is followed by a discussion of those results and the authors' conclusions.

# Moral case deliberation

Certain issues in healthcare practice can be perceived as morally problematic by healthcare providers. This concerns situations in which uncertainty occurs regarding what is right to do. These issues are apt for moral case deliberation (MCD). MCD is a structured method for investigating these moral issues. An MCD focuses on a case presented by one of the participants. This case must involve a concrete, personal experience from the past or present, not a hypothetical situation (Stolper et al., 2016). Participants in MCD in healthcare are often healthcare professionals (doctors, nurses, paramedics), but might also include managers, family members or even patients themselves. Under the guidance of a trained facilitator, the group will investigate the case.

The main purpose of MCD is not to arrive at a solution, but to foster critical reflection on the ethical issue at hand. Underlying values associated with the issue at stake in the case are scrutinized (Stolper et al., 2016). During MCD, participants explore what is important to themselves and other participants. The facilitator guides them in sharing and exchanging their moral considerations with each other. In this way, the issue is jointly examined and perspectives on the case are broadened. MCD is not about proposing statements or convincing an opponent, but about creating space to think about the case together. By exchanging various perspectives, a 'fusion of horizons' (Gadamer, 1960) among the participants can be achieved. The underlying aim is to search for common ground between one's own and others' experiential horizons, in order to understand one another better and develop a richer, more complete understanding of the situation.

To structure the discussion, the facilitator uses a specific conversation method. Several such methods have been developed (Van Dartel & Molewijk, 2014). A familiar option is the 'dilemma method' (Molewijk & Ahlzen, 2011; Stolper et al., 2016) in which a key step is the analysis of the case in terms of perspectives, values and norms. It is customary to

produce a chart or table listing the perspectives of all persons involved in the case, known as the 'stakeholders'. Cultural and religious norms and values can be part of personal perspectives. Our research concerns the extent to which this is addressed by facilitators and whether or not this is questioned by facilitators. The participants in the MCD session seek to identify the values which underpin those perspectives, the norms which serve to concretize the values, and possible courses of action. The norms and values concerned are the personal visions of the stakeholders. Those of stakeholders who are not actually present during the discussion, such as the patient or his family, can also be explored by the group by means of accounts provided by those who know them well (Widdershoven et al., 2016, p.73). Other deliberation methods also explicitly address values.

# **Research methodology**

# **Data collection**

This study forms part of a larger research project examining the relationship between MCD and tragic situations. In healthcare practice, care providers can be confronted by a tragic situation in which they must make decisions which will have far-reaching consequences. To what extent can MCD help them make those decisions? We investigate the role of MCD in dealing with tragic situations by looking at harm, worldview and emotions. This article focuses on the aspect of worldview.

Semi-structured interviews were held with a number of MCD facilitators who were asked to give examples of MCD sessions they had conducted and to briefly explain the process and outcomes. Facilitators using the dilemma method were asked about the role of worldview. Respondents who do not use the dilemma method were asked whether the aspect of worldview is incorporated into their favored approach and, if so, how.

The following criteria were used to select respondents:

- A minimum of 1 year's experience in MCD facilitation.
- Currently working in healthcare (hospital or psychiatric clinic).
- Representative distribution in terms of gender, age, professional background and field of operation.

Twelve facilitators were interviewed: six male and six female. They represent a wide range of disciplines and include three medical specialists, one nurse manager, one paramedic, two clinical ethicists, two healthcare managers and three spiritual counsellors. The respondents have acted as facilitators with various groups. Six work in hospitals, three in mental healthcare, and three in both. The facilitators use (or have used) a range of MCD methods: eight use the dilemma method alongside other methods, while four use only alternative methods. A summary of characteristics of respondents is given in Table 1.

		(n = 12)	
Scale		Distribution	%
Sex	Male	6	50
	Female	6	50
Age	Mean (SD)	48.75 (10.6)	
	Range	30-68	
Discipline	Clinical ethicist	2	16.6
	Spiritual counsellor	3	25
	Medical specialist	3	25
	Paramedic	1	8.3
	Healthcare manager	2	16.6
	Nurse manager	1	8.3
Healthcare type	Hospital	6	50
	Mental healthcare	3	25
	Both	3	25
MCD methods used	Dilemma method alongside other methods	8	66.6
	Alternative methods	4	33.3

#### Table 1. Baseline characteristics of respondents

With the respondents' consent, all interviews were recorded, transcribed and anonymized by the first author and an assistant. The VU University Medical Research Ethics Committee determined that the study does not fall under the requirements of the Medical Research with Human Subjects Act (WMO) as no actual interventions were performed.

# Data analysis

The researchers aimed to identify the key elements of addressing worldview as part of MCD, based on facilitators' personal experiences. Those experiences were defined as broadly and openly as possible using the grounded theory approach as developed by Charmaz (2006). The choice for grounded theory was made because we wanted to take the views and experiences of facilitators in moral case deliberation as a starting point in our research. The grounded theory approach implies not operationalizing the concept of worldview from a theoretical perspective beforehand. Data are collected by inviting respondents to present their own views and experiences and by subsequently analyzing this data.

Data analysis was carried out in three stages. The first stage involved open coding: the first two interviews were coded independently by two researchers and the results discussed by all three researchers. The topic list for subsequent interviews was then refined. The next two interviews were coded by the first researcher, after which the three researchers discussed the coding tree. The first researcher then conducted another eight interviews, two of which were co-coded by a research assistant.

During the second stage—focused coding—all codes were abstracted, overlapping themes and subthemes examined and their codes discussed by the first two researchers. This produced codes for 15 subthemes, formulated as gerunds or participles (verbs ending in '-ing') in accordance with Tweed and Charmaz (Charmaz, 2006; Tweed & Charmaz, 2012). Gerund-based coding ensures a focus on actions rather than concepts, retaining a closer connection to the data (e.g., 'devoting attention to different visions' rather than just 'different visions'). This approach suited our study since we sought to investigate how worldview is actually addressed in MCD practice.

The third phase—axial coding—examined the relationships among and patterns between the various themes, after which the over-arching themes and subthemes were refined and the final categories formulated. All authors agreed with the final set of categories, themes and subthemes.

# Results

This section describes the categories, themes and subthemes identified. The role of each theme in addressing worldview is discussed, as identified by both the respondents working with the dilemma method and those who favor other methods. A summary of the categories, themes and subthemes is given in Table 2.

Category	Theme	Subtheme
Explicit role of worldview	Worldview of participants	Worldview of the patient Worldview of the professionals
	Approach of facilitators	Avoiding stereotyping Devoting attention to different visions
Implicit role of worldview	Core values/inspiration behind values	Core values within the dilemma Professional inspiration Foundation of values Perspective of a good life
	Experiencing spiritual fulfillment	Fulfillment through connection The spiritual and existential dimension
	Lack of appropriate terminology	Difficulty of open discussion Embarrassment
	Approach of facilitators	Avoiding emphasis Thematization via norms and values

Table 2. Summary of the key elements in addressing worldview

# Explicit role of worldview

The first category is concerned with the explicit role of worldview within MCD. This role is linked to clearly visible forms of religious beliefs or traditional belief systems. We first consider the worldview of the participants before discussing how the facilitators use this aspect to steer the discussion.

# Worldview of participants

# Worldview of the patient

Worldview is relevant if it affects the specific case under discussion. This will certainly be the case where the dilemma involves patients with a clear religious background, such as practicing Jehovah's Witnesses, Muslims or members of the Jewish community.

We have many patients with an Islamic background. We have also had Jehovah's Witnesses on occasion, and have sometimes had to contend with the well-known dilemma of their unwillingness to accept blood transfusions. (Interview 8)

Because we were discussing the Jewish community, we considered the tragic situation of a woman who experienced particularly lengthy menstrual periods. It is not permitted to

have sex during menstruation. Ovulation occurs after the onset of menstruation, so if you are not permitted to have sex during this period there is very little chance of conceiving a child. (Interview 9)

Moral standpoints can also be directly linked to the patient's worldview, as illustrated by the following quote concerning attitudes to homosexuality:

I recently had a discussion about a patient of a mental health clinic somewhere in the eastern Netherlands. He is gay. His family had great difficulty accepting him, as did his fellow patients. Worldview certainly plays a part in this situation. (Interview 1)

## Worldview of the Professionals

The worldview of professionals plays an explicit role within MCD if there is a conflict between professional responsibility and personal religion.

The dilemma might concern a nurse who is not willing to assist in certain interventions due to her worldview. (Interview 1)

So, in fact you're being asked whether you would be kind enough to perform five abortions, bring five lives to a premature end, which we are supposed to find acceptable. The patient's worldview has an effect on the entire nursing team. One member of that team is prepared to speak out. (Interview 11)

#### Approach of facilitators

#### Avoid stereotyping

The first subtheme is the need to be aware of, and to avoid, stereotyping. If the situation is one in which worldview plays an explicit role, facilitators warn against the danger of stereotyping.

Of course, we consider the patient's religious beliefs and how they affect what he considers important. You must be wary of falling back on stereotypes or preconceptions. (-) He would not wish treatment to be withdrawn.

You really do have to be very careful not to jump to conclusions. (Interview 1)

I think that many preconceptions and prejudices are at play, whether about Christianity, Islam, Anthroposophy, or indeed any worldview that prompts you to place someone in a certain category. The danger is that any personal exchange about the values which underpin the worldview is overshadowed by the worldview itself. (Interview 5)

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This can also happen because the facilitator omits to have the worldview explained by an MCD participant.

We have an analyst who is half Moroccan. And recently we have had dealings with some Moroccan couples. On one occasion there was an older gentleman who already had eleven children. He had a new, young wife and once again wanted to become a father. Due to his age, however—he was 80—his sperm was not up to the task. The analyst seemed to think that he was letting the Moroccan community down. I advised him not to think of himself as a representative of all Moroccans. We must also beware of allowing your personal vision of what it means to be Moroccan to prevail. (Interview 9)

## Devoting attention to different visions

The second subtheme is 'devoting attention to different visions'. Respondents find it important for facilitators to address differences in worldview.

I think it is a very good thing when you look at those perspectives again and hear why someone is or is not willing or able to do something on the basis of their religion or other beliefs. I can appreciate that. It is laudable. (Interview 10)

It actually depends on my own idea of the case and what it is about. My vision of life, for example. You might believe that being alive is always a good thing provided there is no pain. A lot of people think that way. But there are also people who say that life is worth living regardless of whether there is pain. And even if someone is in pain, that's not to say that they want to end their life. Pain is part of life. This represents a significant difference in worldviews and in people's vision of life itself. (Interview 2)

# Implicit role of worldview

In the second category, we are concerned with the implicit role of worldview in the MCD process. In this category, worldview plays an implicit role in the background and is less clearly linked to world religions. It concerns the basis of core values investigated in MCD. Here, we first discuss core values and the inspiration behind them. The second theme is experiencing spiritual fulfillment. The third theme is the lack of appropriate terminology which would allow one's worldview to be discussed openly, while the fourth theme is the question of how facilitators respond when implicit attention is devoted to worldview.

# Core values and inspiration behind those values

#### Core values within the dilemma

The first subtheme concerns the implicit presence of worldview in the core values relevant to the dilemma. In essence, core values are fundamental beliefs about what makes life

valuable and worth living. They are, therefore, a part of the worldview. Devoting attention to core values creates awareness of what is important.

I always find it a sort of revelation when I realize why I stand for the things I do. I think it is wonderful (-) that you become self-aware like this – oh yes, I understand now. I do this because I believe that, and I find it extremely important. I live on the basis of my norms and values, so I do things in a certain way. (Interview 10)

It is actually the main consideration. (-) Yes, of course it's about what you find important, what you consider worth pursuing. And it is about your own perspective of life. That might be a religious perspective or a secular one. It is all about worldview, nothing more or less. (Interview 1)

#### Professional inspiration

The second subtheme is worldview as professional inspiration.

(-) and the other one says, 'I have that at-home feeling' I remember from nursing or whatever, why I actually do this work. I want the residents to have that same feeling. And he adds, I can't remember finding that feeling so important. (Interview 5)

If I ask people about it, they say, 'at last we have some opportunity to talk openly about our work and we can link it to the reasons we opted for this profession in the first place.' In other words, we talk about inspiration, or the values and principles that are important to our work. (interview 7)

# Foundation of values

The third subtheme is worldview as the foundation of values. The respondent indicates that worldview is the inside, the basis providing nutrition to values. Values are inspired by worldview.

We must then try to realize that the worldview is actually the inspiration to arrive at certain values. And it is those values which form the basis for further discussion. (Interview 4)

This can be difficult to talk about, because worldview is personal and less readily articulated, as is illustrated by the following quote:

I could say that values form the exterior of one's worldview. If you ask about worldview, you are actually asking about the inner part behind the values. We do dare to say something about our values. They are the outer casing and they are in contact with each other. We are used to stating them. Those values are fed, and what feeds them is the inside part of the worldview. This is rather more personal because it is often less logical,

less readily articulated. Some people can be embarrassed by their worldview. Perhaps it is not fully developed, or so full of dogmatic reasoning it is entirely inflexible. (Interview 12)

## Perspective of a good life

The fourth subtheme is the worldview as the perspective of a good life.

I remember one MCD which I found particularly difficult. It was about an unborn baby who had been diagnosed as having a cleft lip and palate. (-) That is something that cannot be repaired completely but it is possible to bring about a significant improvement. Nevertheless, the parents were insisting that the pregnancy should be terminated. I asked the group to imagine that child playing with his friends, normal and intelligent in every way apart from that one little defect. What is a 'good life'? (Interview 11)

# **Experiencing spiritual fulfillment**

## Fulfillment through connection

As the first subtheme in this category, respondents suggest that worldview is an implicit consideration in terms of shared spiritual fulfillment. This is recognized as the experience of a mutual connection between the participants in the MCD process.

MCD offers a way forward as well as an opportunity to speak openly and to reflect on an issue together, whereupon everyone has a much clearer idea of where we stand. I think it is also an opportunity for emotional processing, which may sound high-flown, but MCD should allow time and space for this. In this sense, it is cathartic for the participants. (Interview 3)

Worldview forms a prominent component of MCD because the participants experience it as a unique moment, for which the facilitator might even use a word such as 'sacred'.

I think of these as truly sacred moments. (-) Something actually occurs... I think it is mainly the emerging connection, not only with each other but with the tragic situation. (Interview 2)

# The spiritual and existential dimension

The second subtheme is the spiritual and existential dimension of seeking the 'right' course of action.

... That is something I find almost spiritual – that MCD sets out to determine what I consider to be right and proper, the part I wish to play with regard to others, and whether I will actually be able to do so. (Interview 6)

But it is almost a sort of existential vision of the nature of reality. You're saying that the world is not as it should be, whether by fault or design, so we can speak of a tragic

situation. (-) You would need to be wearing blinkers to think that nothing is wrong. But the question is, how do we see precisely what is wrong? How do we describe the situation in words? Here, worldview plays a very significant implicit part, although in my experience it does not often manifest itself in an explicit way. (Interview 4)

### Lack of appropriate terminology

#### Difficulty of open discussion

The first subtheme in this category is the difficulty of discussing worldview due to the lack of a common terminology. Respondents indicate that in the current secularized society it is difficult to talk about worldview, because the religious language is no longer common.

I am convinced that worldview is a very important part of people's lives, but my work has taught me that most people are unable to discuss their worldview fully because they cannot find the right words. For the same reason, it is difficult for me to broach the subject and I am reticent to do so. (Interview 12)

I would like to learn more about how worldview can be expressed in words, and this would probably be similar to the language we use to describe values. I hope that we will develop appropriate terminology together, and by 'together' I mean as a society. I see a certain linguistic paucity and helplessness, or at least clumsiness, when it comes to talking about abstract concepts such as worldview. Society as a whole has no common language, although certain groups such as religious communities have made moves in this direction. Nevertheless, the terminology remains fragmented and inconsistent. (Interview 12)

#### Embarrassment

The second subtheme concerns the embarrassment that people might feel when discussing matters of worldview.

Personally, I never inquire about someone's worldview, perhaps because I sense a certain embarrassment, possibly due to the sheer difficulty of articulating very more abstract concepts, intuitions and ideas. (Interview 12)

Worldview in the general sense is sometimes brought up, but personal beliefs, religious or otherwise, are not. I get the impression that people find these matters too private to be discussed in an open setting such as an MCD group. As facilitator, one should probe and ask questions, but it would be wrong to embarrass participants or intrude in things they prefer to keep to themselves. (Interview 3)

During one recent MCD session, worldview was certainly raised by the person whose case we were discussing. 'I am religious', he told us. I did not ask him to explain further. Faith and religion are very broad terms. However, it felt almost like an admission of vulnerability. It is nevertheless important to understand why he opts to take a certain course of action. (Interview 9)

## **Approach of Facilitators**

## Avoiding emphasis

The first subtheme in this category is that the facilitator should avoid emphasizing worldview. There are various reasons for this. Doing so might, for example, hamper the discussion while some people may consider it inappropriate to talk about such matters in the hospital setting.

No, absolutely not because it really stands in the way of open discussion. If I announce that I am a protestant Christian, this creates all sorts of images in other people's minds, none of which are likely to be particularly helpful. The other participants might jump to conclusions, or maybe I will suddenly think, 'oh right, in that case I probably shouldn't be in favor of euthanasia.' (Interview 6)

I would be very wary of doing so. (-) I'm mindful of being in the hospital setting, which is not really the place to seek philosophical depth. You are satisfied if people realize that you believe in your point of view and are happy to accept it. That is often enough. You might wish to pursue greater depth but I don't really see that as my task. And given the time involved, it would not be appreciated. However, if you all want to enter a monastic retreat for a weekend and seek depth there, why not? That might be useful. (Interview 2)

#### Thematization via norms and values

Although facilitators generally avoid using the term 'worldview', they do investigate worldview aspects by asking about norms and values.

I never ask directly about worldview or religion, but I do enquire about what a person considers important. And I use that information. Someone whose worldview is based on anthroposophy, for example, might believe that nature should be allowed to take its course and medical interventions kept to a bare minimum. Muslims might object to the administration of morphine because 'when you die, you must be able to look Allah in the eye.' That is my approach – I always take norms and values into account. (Interview 5)

I do not ask about worldview to determine how a person sees a certain dilemma, but if we are discussing, say, euthanasia and someone says 'no, I really couldn't', I find it useful to ask questions. What are the values on which he bases his objections? (Interview 10)

If people want to say something based on their worldview, that's fine too. But I would not ask about worldview outright, at least not immediately. I would be more inclined to ask what particular values are important in this situation. (Interview 7) A similar worldview can result in different values.

What most interests me about someone's worldview is the values that are important within it. I can say that I am a protestant Christian, and perhaps you are too. But you may be a member of an entirely different church or denomination, or have an entirely different family background. As a result, your views about right and wrong may differ from mine. (Interview 6)

One respondent stated that worldview is examined during a session by means of general questions about the participants' core values.

But what I often do is to go around the group and invite people to say a few words about the values they find important based on their upbringing. I might also ask what values they try to instill into their own children. These are often the person's core values. (Interview 6)

## Discussion

Using the grounded theory approach, we investigated the role of worldview in MCD.

The grounded theory approach implies not operationalizing the concept of worldview from a theoretical perspective beforehand. For our purpose, we defined worldview as "fundamental beliefs about life, death and suffering that structure people's ideas on how life events are related" (Littooij et al., 2016a, p. 7). We have chosen this definition, because it is broad, inviting respondents to present their own views and experiences. The concept as defined is not opposed to current approaches in religious studies. Smart distinguishes 7 dimensions of worldviews: philosophical or doctrinal (beliefs), ethical, experiential, material, social, mythic and ritual (Smart, 1991). Our concept of worldview is broad enough to encompass these dimensions, but it refrains from explicitly addressing them during the interviews. Our results show that respondents address most of the dimensions distinguished by Smart, although the material and ritual dimensions are not present. A reason for this may be that MCD focuses on words and conversation, not on material objects or rituals.

The results reveal that worldview plays both an explicit and an implicit role.

Worldview becomes relevant in a number of specific examples, all of which are linked to clearly visible forms of religious belief. Respondents cite cases involving followers of the Islamic and Jewish faiths, as well as Jehovah's Witnesses. The examples often involve some moral issue, such as objections to abortion, euthanasia or homosexuality. A conflict between religion and professional responsibility can arise in care givers who have such objections to some degree, whereupon the fulfilment of their professional duties results

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in a crisis of conscience. There may also be situations in which the professional is unable to accept or respect the patient's views or beliefs.

Specific examples of religious worldviews can all too easily lead to assumptions based on stereotypes. Schweda et al. (2017) draw attention to the risk of stereotyping in end-of-life decisions, describing the variation and complexity of the relevant cultural and religious aspects. "There are no clear-cut positions anchored in nationality, culture or religion. Instead, attitudes are personally decided on as part of a negotiated context representing the political, social and existential situatedness of the individual." (p. 1) The MCD facilitator should, therefore, devote attention to the various perspectives at play within the group and remain alert to any preconceptions that may exist in order to avoid the pitfalls of stereotyping.

Facilitators state that they consider it important to take the various visions into consideration. The respondents emphasize that worldview colors our moral beliefs. This bears out the findings of Turner's (2003) study examining bioethics in a multicultural world. He notes that "...religious convictions and cultural norms play significant roles in the framing of moral issues" (p. 99). Turner also stresses the importance of taking the particular moral world of patients and their family members into account. Cultural and religious traditions determine how people view birth, illness, suffering and death. A more anthropological approach to ethical issues can help to raise awareness of the role of culture and religion in MCD (Turner, 2003).

Worldview also plays an implicit role, being the basis of core values investigated in MCD. Those core values represent fundamental beliefs with regard to the value of life: what makes life worth living? Careful discussion of the core values can therefore help MCD participants to identify the crux of the issues at hand (Widdershoven et al., 2016, p. 73, 79; Hartman et al., 2016, p. 78).

One specific area in which worldview (in the form of core values) can further the MCD discussion is the professional inspiration of caregivers. Rushton (2017) points out that keeping sight of one's original motivation for practicing a certain profession helps to promote resilience and the ability to function well. According to Geller et al. (2008), motivation includes the desire to be of significance to the patient.

Worldview is also seen as the inner part and inspiration behind values. It thus is tangent to the base of values and displays the foundation on which values are grounded. Worldview shows the fundamental nature of values. In order to clarify the fundamental nature of values, more explicit attention for worldview might be useful during MCD and contribute to the deliberation. We would advise facilitators to be alert to statements or terms which may reveal something about the speaker's worldview (Alma, 2008, p. 62). However,

facilitators point out the difficulty in discussing this inspiration, which involves matters which are sensitive and do not lend themselves to verbal expression.

During the MCD process, participants attempt to identify what constitutes 'a good life'. By encouraging explicit discussion of this topic, facilitators can thematise worldview. Doing so will also make participants more aware of their reasons for making choices.

MCD is also beneficial in that it can bring about fulfillment through connection and touch upon the spiritual and existential dimension of ethical issues. The element of connection implicitly refers to *religion*, in the sense of the Latin *religare*, one meaning of which is 'to bind together'. This implies both the connection with important topics and the connection with each other. The spiritual and existential dimension touches upon hope, inspiration and healing (Alma, 2018). The relationship between worldview and healing shows marked similarities with that between worldview and coping (Balboni et al., 2007; Körver, 2013; Pargament & Ano, 2006; Puchalski et al., 2009). The literature on the relationship between worldview and coping notes that, next to support by talking, support based on rituals can be effective. Rituals can enhance social cohesion and the 'sense of community' (Ladd & Spilka, 2013, p. 445). Perhaps the steps of MCD can themselves be regarded as creating a ritual which may enable participants to deal with difficult moral issues in life.

Addressing worldview is not a simple matter, for various reasons. There is no common language to describe the various aspects involved, and the use of a 'highblown' term such as worldview may itself cause some embarrassment. These limitations account for the changing position of worldview—and in more general terms, religion—in today's society. Under the influence of modern rationalism, existential themes have been banished to the private sphere. In the public domain, people are more concerned with understanding the causes and effects of more concrete phenomena (Vanheeswijck, 2008) rather than 'the final questions' (Alma, 2018, p.53).

Bauman and Donskis (2013) suggest that there is growing reticence to discuss worldview, and a gradual loss of appropriate terminology, due to secularization and individualization. The search for moral and spiritual significance is increasingly a solo undertaking (Alma, 2018, p. 54). The disappearance of institutionalized, organized worldviews with moral, existential and spiritual authority in western society means that there is no longer a common language which would enable people to talk to each other about their vision of a good life, or to reflect upon the social constructs which could inform their actions and decisions. (Alma, 2018, p. 54).

Worldview is an implicit component of any discussion about norms and values. Values can form a starting point for a reflection on what is valuable and worthwhile in life. Here, we must ask whether a more explicit use of the term 'worldview' would increase the cohesion of the various values within someone's vision of 'a good life', thus furthering

their thematization. We propose to further explore this potential addition to the MCD methodology, as has been done regarding the explicit thematization of emotions (Molewijk et al., 2011a, b).

## **Strenghts and limitations**

As far as we know, this is the first study examining the visions and experiences of facilitators on addressing worldview in MCD. Our study, however, has some limitations. The interviews were conducted by a researcher with a background in pastoral care. This may have influenced the interviews. A second limitation is that the study was conducted in the Netherlands, in a largely secularized society. This may limit generalization to other countries. A third limitation is that the interviews were held with facilitators. Interviews with MCD participants might give information about their experiences and complement the results.

## Conclusion

According to the facilitators taking part in this study, worldview plays both an explicit and an implicit role in the MCD process. The explicit role concerns the religious beliefs of patients and professionals. This calls for alertness in order to avoid stereotyping. The implicit role involves the core values, intentions and inspiration of the participants. Aspects of worldview are also at play in the creation of connection between participants, and their experience of the spiritual and existential dimension of ethical dilemmas. In order to clarify the fundamental nature of values, more explicit attention for worldview might contribute to the deliberation. Including aspects of worldview might enhance the methodology of MCD, allowing greater opportunity for reflection on aspects for which appropriate terminology is lacking in our modern society. However, this should be done with caution as the term 'worldview' might be interpreted by participants in terms of religious and personal beliefs, rather than as an invitation to reflect on one's view of the good life as a whole.

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## **Authors' Contribution**

BS contributed to the conception of the study and participated in its design, development and coordination and was involved in drafting and revising the manuscript. GW contributed to the conception and participated in the design and development of the study and was involved in drafting and revising the manuscript. HA contributed to the conception and participated in the design of the study and was involved in drafting and revising the manuscript. All authors read and approved the final manuscript.

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## Availability of Data and Materials

The dataset that supports the conclusion of the article is available in Dutch.

## Declarations

Conflict of interest The authors declare that they have no conflict of interest.

## **Ethics Approval and Consent to Participate**

The respondents gave their approval and consent to participate. Respondents are indicated by number instead of by name or function. All names, places and other characteristics of the participants involved are changed and therefore untraceable. The VU University Medical Centre's Medical Research Ethics Committee declared the study did not fall under the Medical Research (with Human Subjects) Act (WMO), as no interventions were performed. Consent for Publication The respondents gave their approval for publication.

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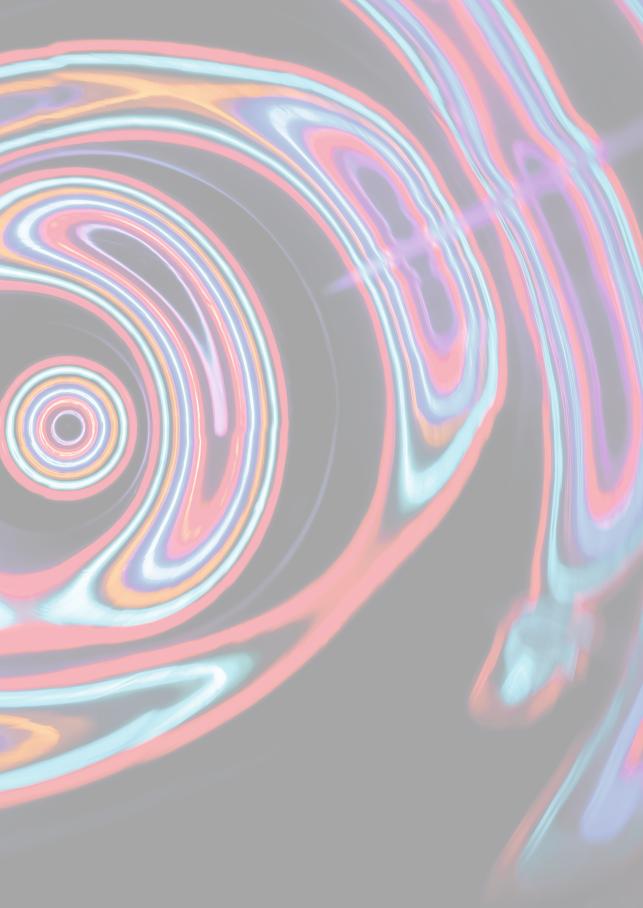
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#### Chapter 5

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The role of worldview in MCD



# 6. General discussion

# Introduction

The central question of this thesis is: How can healthcare professionals be supported in dealing with tragic situations through MCD? This question will be answered in this chapter. First, we will present a summary of our findings. Next, we will reflect on the findings, focusing on areas of tension. We will examine how care professionals can deal with these tensions in practice and how facilitators can address them during MCD. We will also discuss the strengths and limitations of the current study, and formulate recommendations for practice and for further research. We end with a conclusion on the significance of MCD in tragic situations.

# **Summary of findings**

This thesis examines how healthcare professionals can be supported in dealing with tragic situations through MCD. What is the value of MCD in such situations? What specific demands are placed on facilitators? Can the findings of our research support and strengthen the facilitation process? In this final chapter, we take stock of the research described in foregoing chapters.

First, we investigated how participants experience the support provided by MCD in dealing with a tragic situation. We found that a tragic situation has considerable impact on care providers. Such a situation is inescapable and greatly affects the persons involved. It therefore comes as no surprise that care providers feel powerless. We also saw that tragedy can go hand in hand with a potential erosion of human dignity. Yet, tragedy is not only negative; by allowing us to experience fragility and vulnerability, it can also reveal what we deem precious in life and what makes life worthwhile. MCD can help care providers to reflect on a tragic situation. In order to better understand how MCD can support care providers in dealing with tragedy, we investigated the views and experiences of facilitators regarding three aspects of addressing tragedy in MCD, namely harm, emotions and worldview.

First, MCD can support care professionals by creating **awareness of harm**. When the dilemma at the heart of the case under consideration is carefully formulated, the potential harm associated with each of the treatment options becomes clear. Open dialogue about this harm brings the tragic dimension of the situation into sharp focus. Professionals must be aware that a choice has to be made, and that every possible course of action entails some degree of harm. Facilitators can support participants in taking into consideration the need to act in a tragic situation and accepting the limits of their actions.

Second, MCD can help care professionals in **acknowledging emotions**. Tragic situations affect not only patients but also their care providers. A tragic situation is painful; this is inevitable. Although we often prefer to ignore or suppress negative emotions, it is

important to acknowledge them and to examine their significance. Emotions cast light on underlying norms and values which can show MCD participants what matters to them. When MCD provides the opportunity to discuss and reflect on emotions, the examination of the moral dilemma is fostered and participants can arrive at the crux of the matter. Yet, facilitators should be careful in providing room for emotions. On the one hand, they should assist participants in recognizing and expressing emotions, on the other hand they should help them to find the required distance to reflect on emotions.

Third, MCD can encourage participants to **address worldview**. Our findings show that, especially in tragic situations, MCD touches upon the existential dimension of care. MCD offers the opportunity to think about and reflect on worldview as the source of personal values. Devoting attention to worldview in the context of a tragic situation enables MCD participants to explore their view of life, and to discover what is particularly important and valuable to them in their care practice. This is not just a matter of formulating general principles; it also implies applying them to the concrete situation. Facilitators can support participants to consider the existential aspects of the tragic situation on the one hand, and invite them to explore what can be practically done on the other hand.

## **Reflection on the findings**

Our results show that MCD can support healthcare professionals through fostering awareness of harm, acknowledging emotions, and addressing worldview. In this section we will reflect on our findings. We will specifically focus on the tensions regarding harm, emotions, and worldview, both in care practice and in discussing moral issues in MCD. We will also argue that virtue ethics can provide insights in what is needed in order to deal with these tensions in care practice and in how facilitators can support care providers participating in MCD.

Harm, emotions and worldview – are evident in the series of moral case deliberations studied in Chapter 2. These meetings involved a markedly tragic situation: the case of a 38-year-old pregnant woman who had been diagnosed with glioblastoma. The tumour was advanced and inoperable. The patient expressed a strong desire to continue her pregnancy. The dilemma facing care providers was: (A) we treat the patient (with a feeding tube/antibiotics to improve the child's prospects), or (B) we give no further treatment but restrict ourselves to palliative care. The negative consequence of option A was formulated as 'unnecessary suffering', while that of option B was 'poor prospects for the unborn child'. Each alternative would have a direct impact on patient care. In this section, we will refer to the MCD series about this case, while reflecting on the tension in care practice and in MCD regarding harm, emotions and worldview.

### Awareness of harm

Awareness of harm clearly involves a tension. On the one hand, care providers are asked to provide treatment. The patient depends on them for good care. On the other, treatment will cause harm and that harm must be acknowledged. Here, we see a tension between the demand for heroic action on the one hand, and the need for acceptance of contingency, and thus the acknowledgement of the limitations of such action, on the other hand.

The acceptance of contingency does not mean that joint deliberation is no longer required. Some might suggest that it is better to say nothing, since the harm is inevitable and there is nothing that can be done to avoid it. Where a situation cannot be changed, the only option is acceptance. This argument can be doubted. Remaining silent is problematic, for three reasons. First, open discussion in the MCD setting will identify the exact nature of the harm, and hence precisely what is at stake. Second, exploring all perspectives may well cast the situation in a new light. Sharing knowledge and experiences may offer additional information about the case, perhaps enabling a different moral judgment to be formed. It is even possible that new treatment options will emerge. Hearing others' values enables participants to enrich and adjust their own values. Third, the discussion of harm provides support to all participants, both emotional and practical support in arriving at a decision about the dilemma.

The tension involved in addressing harm has consequences for the relationship between ethics and tragedy. For some, ethics and tragedy are two separate domains. Ethics is regarded as the area in which the care provider can change something (in terms of behaviour or values), while tragedy is the area in which care providers must learn to live with whatever life brings (Walton, 2006, p. 326). But is this distinction valid? Our research shows that much can be done, even in tragic situations. The findings demonstrate the importance of encouraging discussion between care providers about the choices to be taken. MCD helps to formulate and specify harm, and how much of that harm can be put right, or 'repaired'. At the same time, MCD participants come to realize that there are limits to heroic action, and this helps them to cope with the tragic situation more effectively.

In the case of the pregnant woman, the tension concerning harm is clearly visible. The MCD participants discussed the harm that the two options would cause to the patient and her unborn baby. The dialogue covered factors which were beyond the care providers' ability to change, as well as what they could and should do given the circumstances.

Perspectives on harm differ. What one person might regard as serious harm is seen as less serious by another. Personal background and recollections of earlier situations play a part here. One of the care providers involved in the case of the pregnant woman told the group that her own mother had died of a brain tumour. She could therefore empathize with the patient's relatives and was acutely aware of the values that informed her own role as care provider. Personal background can thus influence the individual's perspective on harm. The case also clearly demonstrates that the decision cannot be made by one person alone. Such a heavy responsibility must be shared with others. Care providers need each other in order to discuss the values that underlie the dilemmas affecting mother and child. Dialogue can help to establish the appropriate course of action.

The intricate relationship between ethics and tragedy is also visible in the MCD about this case. The participants developed an awareness of a tragic situation in which the options were very limited. At the same time, they were required to make a choice while accepting the unchangeable nature of the situation. We thus see that ethics and tragedy are not separate entities. Rather, they are closely intertwined components of the care provider's daily practice. The interrelationship between the two raises various issues to be considered during the MCD process.

What are the implications of the tension related to harm for the MCD facilitator? The first important step is for the facilitator to ask participants to consider the harm that will ensue from each of the two options, and to describe that harm in real terms. Next, he or she must help participants to explore the various perspectives of harm, encouraging open discussion. The facilitator should foster the acknowledgement of harm, but also ensure that this acknowledgement does not detract from participants' ability to act. The various perspectives on harm should be examined. How do participants regard the harm? The third step is to devote attention to the balance between heroic measures and acceptance of harm. At the end of the MCD, participants should agree on a course of action, noting also those matters which remain unresolved. MCD therefore goes a step further than 'this is the option that will cause least harm and is therefore the one we must choose'. The process must include the fundamental step of acknowledging the harm that cannot be avoided or repaired.

The tension between the need to act and the need to accept contingency is a permanent feature of a healthcare professional's life. How can care providers deal with this tension, and what role can MCD play? One answer to these questions can be found in virtue ethics. Virtue ethics is not primarily concerned with what we should or must do, but with how we can pursue personal development. According to Aristotle, a virtue is an attitude or disposition (Van Tongeren, 2016, p. 103). It concerns a quality of character which is developed over the course of one's life. A virtue entails the desire to improve one's attitude and the willingness to devote time to practice this. Virtue ethics involves seeking the right middle between extreme responses. For a professional, coping with harm requires virtues which are practised on a daily basis. He or she must learn to live with the fact that not every problem can be solved nor every ill cured. At the same time, this must not deter him or her from taking action. This implies a precarious balancing act. MCD can offer support and the facilitator has an important role in this regard. If the participants move too quickly to a discussion of the action to be taken, he or

she must encourage them to first identify and acknowledge the potential harm. If the participants cannot progress beyond the aspect of harm, he or she must encourage them to start considering action.

#### Acknowledging emotions

Emotions are indicators of a person's underlying norms and values. What implications does this have in terms of showing or hiding emotions during the MCD process? How do participants discover the norms and values that underlie emotions? This theme also implies a tension, since there must be an opportunity to express emotions but it is also necessary to create distance in order to discuss and reflect upon them.

In the first instance, it is crucial that the MCD participants acknowledge their emotions. Moral dilemmas relating to tragic situations do evoke emotions, and these can differ from one person to another. It is important to acknowledge this (Baart, 1993). Dealing with emotions is not easy, especially against a background of far-reaching decisions. Ford and Dudzinski note that moral dilemmas bring an emotional burden and can continue to follow us for some time (2008). Thorne et al. describe how dilemmas can keep us awake at night (2018). Emotions warrant attention and there must be adequate opportunity to express them. This makes the engagement of the MCD participants visible and shows what effect the tragic situation has had upon them. Emotions must be experienced in full before they can be processed. The case of the pregnant woman raised many emotions among the MCD participants. The tragedy was acutely felt not only during the initial description of the case but in all subsequent steps. Participants state that having the opportunity to express their emotions was itself a source of support. The structure of the MCD provided the distance needed to engage in reflection on those emotions. One respondent noted the apparent conflict between expressing emotions and maintaining distance, stating that MCD must not become a 'business-like' discussion. It must allow room for emotions, while the discussion must also provide enough structure to permit adequate reflection.

Nussbaum stresses the importance of emotions (Nussbaum, 2001b). She subscribes to the Aristotelian theory of emotions. With Aristotle, Nussbaum emphasizes that in situations that evoke strong emotions, it is important to seek the right middle. The right middle between excessive anger and total indifference, for example, is calmness of character which allows emotions to be channelled in a healthy manner. Calmness of character is a virtue which must be practised and assimilated. MCD can provide the opportunity to do so. Through regular joint deliberation on particularly difficult situations, participants systematically examine their emotions which can help them to cope with those emotions in future. This benefits care providers, the department and patients alike.

The right middle will vary according to the situation and must be sought in MCD by a process of trial and error. There is no mathematical formula. Nussbaum demonstrates that care providers facing a tragic situation cannot rely on a simple cost-benefit analysis

(Nussbaum, 2000). This approach will not work given the nature of the question they are required to answer. It is not possible to arrive at an answer by weighing options in terms of more or less harm. Considering only the costs and benefits of each option will not reveal what is most likely to contribute to the good life (Manschot, 2003, p. 237).

In our research, we saw that the role of emotions differs according to the phase of the MCD process. We distinguished the initial phase, the reflection phase and the concluding phase. In the initial phase, there must be opportunity to express and explore the emotions being experienced. During the reflection phase, participants examine what an emotion actually means. In the concluding phase, the objective might be to accept the emotions and appreciate their value. Feelings of relief may or may not then arise, depending on whether participants regard the question as resolved. These phases overlap. The incorporation of emotions into MCD does not demand a separate step. Rather, structured attention for emotions should be a component of all the standard steps of the process. Success will depend on the skills and expertise of the facilitator.

What demands does this place on the facilitator? The role of the facilitator is to encourage participants to question each other. The facilitator might do so by inviting those participants who are keeping their emotions at a distance to explain how the situation has affected them, or by encouraging them to question other participants who are showing more their emotions. Alternatively, the facilitator might invite those participants who are showing their emotions to explain the aspects of the case that have affected them. There may be participants with extensive experience in healthcare practice who have found ways of dealing with tragedy. The facilitator might invite them to describe their way of dealing with particular reference to the case under discussion. The task of the facilitator is to guide the dynamic process of examining emotions according to the phase of the MCD process.

#### Addressing worldview

Our findings show that addressing worldview helps MCD participants to deal with tragedy. While emotions are indicators of values, worldview places these values within a wider context. Here, values are translated into a more comprehensive view of the good life, part of which is recognizing the fragility of life. Once again, specific tensions can be distinguished. First, there is a tension between worldview as a general vision of life and concrete experiences in which worldview is apparent. Second, there is a tension between the existential depth which tragedy demands and the exploration of what can or should be done.

First, let us examine the tension between the general nature of worldview and the importance of the concrete experiences which inform it. Many MCD facilitators are hesitant to explore participants' worldview in any depth. They find it difficult to broach the topic and to find appropriate terminology. This is partly because the word 'worldview' is often

associated with traditional forms of religious beliefs or personal philosophies. Although worldview does have a general character, it is not an abstract vision of life but is rooted in meaningful experiences. MCD offers an opportunity to bring this aspect of worldview to the fore, precisely because MCD itself is concerned with concrete experiences (Molewijk, 2014 p. 24; Stolper et al. 2010; Weidema et al., 2013; Widdershoven et al., 2009) and hence with matters that are of direct significance to the participants. Care providers are affected by the situations they experience and the patients for whom they care. This can be understood in terms of resonance: the world affects us all with its manifestations of various types, and we respond through our speech and actions (Alma 2018, p. 81ff; Rosa, 2016). The absence of resonance can result in alienation. Relationships become meaningless, strange or even threatening. MCD encourages reflection on issues which touch upon one's view of life and its fragility. This can help to ensure that participants do not limit themselves to general terms but are specific about what they consider important. Their experiences then resonate within MCD.

Second, let us go into the tension between existential depth and the exploration of what can and should be done. An MCD session need not be a deep philosophical or theological discussion. Participants are required to reflect but not to lose themselves in questions to which there is no answer. Rather, they must devote attention to the facts of the situation and what is actually possible. Hannes offers a relevant view on tragedy (Hannes, 2019). He states that there is no 'deeper truth' in tragedy, no higher power that controls events or gives them meaning. There is no deeper intention behind suffering. In his view, Western philosophy and theology go too far in seeking depth and meaning. If we wish to know how to deal with tragedy, we should not begin by seeking some deeper meaning within the events that befall us, but move on one step at a time and examine what can actually be done. Hannes uses the analogy of a tightrope walker negotiating a rope stretched over a deep canyon (Hannes, 2019, p. 439). The 'sense' cannot be found in suffering associated with tragedy. The 'sense' is the rope as a whole, the tightrope walker and the journey he makes across the canyon, and the wider setting in which he finds himself. Determining where to place your foot to avoid plunging into the canyon below demands great concentration. What can you do? How can you respond? The MCD process is similar in that it encourages participants to take concrete steps as they attempt to find ways to deal with the moral dilemma. Hannes contends that care providers should not seek deeper meaning in their patients' suffering, but must continue to look 'straight ahead'. Returning to virtue ethics, this entails finding the appropriate middle. That middle will have to provide room for both the existential experience and a focus on action. Although this approach does not attribute depth or meaning to suffering, the participants of MCD must acknowledge the patient's suffering. The tragedy must be stated and addressed. At the same time, the facilitator should encourage participants to devote attention to action. Once again, it is a question of finding the appropriate balance.

Reflection on life questions guides MCD participants towards the best possible response to the patient's care requirement, even where the ethical question is tragic in nature. As one respondent pointed out, the case of the pregnant woman involves a number of questions about life: "As a care provider, what is your attitude towards the problems that you encounter in life? What do you consider important? What are your beliefs and convictions? What is your culture?" These are questions that make life worthwhile and which determine human dignity. Another respondent reported that MCD had encouraged her to think about what she wanted to pass on to her children and how she wished to be remembered. Such questions, asked by participants themselves, are not directly related to medical treatment, but they are indeed concerned with the underlying values which inform medical decisions. In this case, reflection on these questions about life enhanced the ability to add compassion to the unavoidable tragedy. Compassion is itself a virtue to which care providers are moved by others and their experiences. They devote themselves to their patients without regarding them solely as the victims of tragedy. The other is more than their suffering and pain at that moment (Alma, 2021). Compassion and empathy are closely interrelated. It is a question of "having the courage to be with the other in her suffering, and of entering into a relationship with the other which offers some view of what is possible in the given situation" (Alma, 2021, p. 15, here in translation). Compassion again encapsulates the search for balance.

Tragedy can reveal values. According to Nussbaum, admitting fragility can enrich life. Experiences such as love and relationships with others make us more vulnerable, but these are also the very experiences which make life worthwhile. Without such experiences, care providers would function as little more than automata. Nussbaum terms the process 'exposure' (2001 a, pp. 18-21), an important element of an ethical life. The manner in which care providers approach suffering, and what they consider important values in their care for vulnerable patients, are the building blocks of their view of the good life. This view permeates their professional practice, in which values are given form and substance.

The case shows that this is not always easy to achieve. The participants' view of the good life is shaken by the confrontation with the patient's suffering. During the MCD, some participants said that the extreme nature of the case made them yearn for the 'simple' life, without the intrusion of tragedy. One participant stated that he needed "a bit of normality" amid all the ghastly situations he experienced in the hospital. Yet, the situation also made participants see the importance of learning to accept the inevitable. The discussion of impending death of the patient, and probably her unborn child too, made participants aware that, if both were to die at the same time, that might give a certain inner peace. Discussion of a 'dignified' death provided an indication of what is considered the good life and what is needed to attain it.

What are the implications for the facilitator? It can be useful for the facilitator to realize that MCD in a tragic situation is not a general discussion about the meaning

of life or the significance of suffering. Nevertheless, attention should be devoted to the existential depth of the care providers' experiences. This is an inherent part of the process of discovering the underlying values which inform the decision to be made. Reflection on questions about life can help to reveal the options which represent true compassion and are in keeping with the good life. Such reflection can take place during each of the methodological steps of the MCD process. The facilitator must maintain a balance between slowing and deepening the discussion on the one hand, and moving it towards determining the appropriate course of action on the other hand. Because various worldviews are represented, there are likely to be different perspectives on the tragic situation. The task of the facilitator is to ask questions designed to clarify the participants' underlying values and views, and the implications they have for treatment and interaction with patient and family. By sharing views, participants can clarify their thinking and proposed action. In MCD, worldview is not merely abstract knowledge or a set of convictions. Rather, worldview is connected with the practice and experience of the care providers. Seeking the appropriate balance is another form of virtue, and one which the facilitator learns through practice. During the MCD sessions, all participants may also learn how to seek balance.

MCD can support professional care providers in tragic situations by fostering awareness of harm, acknowledging emotions and addressing worldview, and taking into account the tensions identified above. Each of these aspects of tragedy are important, and they add to each other. In the literature on MCD, the importance of emotions has been recognized (Metselaar et al., 2020; Molewijk et al., 2011a; Molewijk et al., 2011b). Yet, focusing on emotions alone is not sufficient, and thematising other aspects of tragedy, such as harm and wordview, can also enrich the deliberation on experiences of tragedy.

Our case study involved an MCD which was facilitated with the dilemma method. Yet, Our findings concerning the views and experiences of facilitators regarding harm, emotions and worldview are relevant for MCD in general. Different methods of MCD can be used in tragic situations. What ties these methods, is that all involve struggling with an ethical issue, examining what is at stake, and seeking how to act on the issue. Creating awareness of harm, acknowledging emotions, addressing worldview and taking into account the areas of tension involved, are relevant regardless of the method used. It is up to the facilitator to consider how to address harm, emotions and worldview and pay attention to the tensions implied in them, so that the development of virtues can be fostered.

## **Reflection on methodology**

In this section we discuss the strengths and limitations of both data collection and data analysis.

A strength of the data collection process concerning the experiences of participants is that it focused on a series of MCD sessions relating to one and the same case. The interviewees' answers were related to the same context and the results revealed the diversity of responses to the same situation. In the qualitative research concerning the experiences of facilitators, respondents were included who use diverse MCD methods. Moreover, we not only interviewed facilitators for whom guiding MCD is their main professional activity, but also physicians, managers and pastoral care providers who have completed training as a facilitator. The results therefore represent, and are supported by, a broad range of facilitators. Discussing tragic situations in MCD is a challenge for any facilitator. Because that was our primary focus, we did not focus on differences between the methods facilitators use.

A limitation of the data collection process is that the interviews were conducted by a researcher with a background in hospital chaplaincy and pastoral care. This may have skewed the interviews somewhat, because the interviewer may have focused on matters relating to worldview, or because the respondents' answers were influenced by certain expectations. We have mitigated this limitation by having persons whose background is in philosophy and ethics participate in conducting the analysis. Concerning the respondents, additional information might be retrieved by including MCD participants with experience of cases representing varying degrees of tragedy, and with participants of various professional disciplines.

A strength of the analysis of the interviews with facilitators is that a standardized method was used, namely the Grounded Theory approach as developed by Charmaz (2006). The analysis focused on the viewpoints and experiences of the respondents. Our study is therefore in line with the hermeneutic research tradition in which qualitative content analysis combines both deductive and inductive elements (Mayring, 2014). The deductive elements are the 'sensitizing concepts' selected for this study (Charmaz, 2003), namely the three themes of harm, emotion and worldview, found in previous literature on clinical ethics, and further elaborated by Nussbaum. At the same time, we remained open to inductive elements deriving from our data. Accordingly, the sensitizing concepts acted as an a priori framework which could be refined based on the research data. This implied a hermeneutic circle (Gadamer, 1960). In the discussion, we reflected on the findings, focusing on the importance of dealing with tensions related to harm, emotions and worldview, and addressed the relevance of virtues in this respect. By relating our findings to Nussbaum's work on tragedy and to virtue ethics, we were able to further develop insight in the consequences of our findings for healthcare practice and for the facilitation

of MCD. Once again, this represents a hermeneutic circle between empirical research and philosophical theory.

A limitation of the data analysis process is that the results were not shared with the respondents, who were therefore not asked whether they recognized our findings. Inviting feedback could have helped to strengthen and where necessary refine the results.

## **Recommendations for practice**

1. Include MCD in training programmes for healthcare professionals and in the formal policy of healthcare institutions

Care providers encounter tragic situations in their day-to-day work. A defining characteristic of tragedy is that it relates to situations in which care providers can see no clear way forwards. In the first instance, they have no ready response to such situations. MCD can help them to overcome their reticence. Although it may at first appear that there is nothing that can be done, our research clearly shows the importance of discussing this type of situation. MCD provides an appropriate structure for such discussion (Molewijk et al. 2008). Through MCD, and the guidance of a good facilitator, emotions can be brought onto a higher plane, becoming not just a private and personal experience but an important aspect of joint deliberation. During MCD, participants share their emotions, the significance of which can then be examined and acknowledged. This process relies on the participants' view of the good life. MCD is the ideal setting in which to foster reflection on the good life in the context of healthcare. Such reflection enhances care providers' resilience and ability to cope with similar tragic situations in future. It reveals that, even given the apparent powerlessness they feel, there are indeed opportunities for action. We therefore recommend that training programmes for care providers devote specific attention to MCD to prepare them for professional practice. We further recommend that MCD be included in the formal policy of hospital departments in order to support care providers who encounter this type of difficult situation.

## 2. Devote attention to the existential dimension of MCD

Our results show that worldview is a theme that warrants attention within MCD on tragic situations. Worldview places values in a broader framework. It concerns our view of the good life and how to address the fragility of life with which tragedy confronts us. Given the importance of existential elements within care, it is essential to reflect on those elements (Alma, 2005; Browell et al., 2014; Puchalski et al., 2019). Many care institutions have chaplains and other pastoral care providers. Their professional background and experience imply that they are used to talking with patients and care providers about tragic situations. They know how to discuss delicate issues such as serious suffering, feelings of impotence or impending death. During MCD they can help to examine and

reflect upon what is important to the participants in the here and now. Although pastoral care providers can encourage discussion, it is important that attention for the existential dimension is not confined to professionals in the domain of spiritual care. It affects all care providers, and consequently all care providers should be involved. It is therefore important that all disciplines have an opportunity to contribute.

3. Practise MCD in tragic situations as part of the facilitator's training

Discussion of tragic situations in MCD demands considerable expertise on the part of the facilitator. Attention should therefore be given to practising the necessary skills. MCD demands that the facilitator gains a thorough understanding of the case, the patient and the tragic situation in which the patient finds him or herself. Participants then become more en-gaged with the outcomes of the discussion, which creates room for compassion (Alma, 2021, p. 5) and empathy: a relationship with the other who is suffering and in pain. whereby tragedy is acknowledged while examining the underlying values which guide care providers' decisions and actions. Practising the specific communication skills needed in tragic situations can be made part of the facilitator's initial training. Refresher training and peer supervision can also be beneficial (Stolper et al., 2015). Peer supervision can help advancing the required expertise, since it entails ongoing learning, closely related to actual practice. As such, it can help to develop the skills needed to facilitate MCD in situations which are to some degree 'tragic'. MCD in such situations must devote due attention to the themes of harm, emotions and worldview, as well as the tensions and conflicts that are inherent in these themes. Our research shows that facilitators experience these tensions, and need training to find the required balance.

## **Recommendations for further research**

1. Attention for the patient's perspective

Our research is concerned with the perspective of the participants in, and facilitators of, MCD relating to tragic situations. We note that care providers' resilience is increased when they enter into open dialogue about the aspects of harm, emotions and worldview in MCD. Further research is needed to examine the relevance of MCD in tragic situations from the patient's perspective. How do patients view the role of MCD in tragic situations? How do they perceive tragedy? And what contribution do they believe MCD has made in the tragic situations which they themselves have encountered? Does MCD help them to deal with that situation? Can the patient's perspective of tragedy be incorporated into the MCD process more effectively? If so, how? One option is to involve the patient, or a family representative, in MCD. However, it is possible that a situation will be simply too tragic to allow this. Also, the patient or family representative may feel overwhelmed by the presence of the care providers and the MCD dynamic (Weidema, 2011). In particularly tragic situations, it might therefore be preferable to first hold an MCD with professionals

only. In less serious situations, it may be productive to involve the patient from the outset. This might reveal hitherto unknown elements of tragedy, which could help both the patient and the care professionals to acknowledge precisely what is at stake.

## 2. Addressing harm, emotion, and worldview in MCD evaluation

We recommend that the evaluation of MCD meetings should devote particular attention to MCDs involving tragic situations. The evaluation might, for example, examine the significance that care providers attach to the opportunity to discuss tragic situations with each other. Our research suggests that the following questions might be asked: (1) Did the MCD devote due attention to harm, emotion and worldview? (2) Were the experiences of suffering and powerlessness on the part of patient, family and care providers adequately acknowledged? (3) Did the deliberation devote due attention to the underlying virtues? The Euro-MCD (de Snoo-Trimp, 2020) can provide inspiration here, helping to gain further insight into both moral teamwork and moral action.

## 3. Investigating the need for other forms of clinical ethics support

In our research, we have observed that there are several ways of providing support to care providers who face a tragic situation. Not all cases will demand a full-blown MCD. Sometimes, an informal discussion over coffee will be enough. There are, however, cases in which MCD will be required, and maybe also a referral to an ethics committee (Albisser Schleger et al., 2012, p. 227ff.). There may be a need for further research to determine the steps to be taken when upscaling ethics support. What do departments actually need in this respect? It may be useful to develop policy in association with a hospital department which acknowledges the need to do so. As part of this research, it may be appropriate to examine what action should be taken if an MCD about a tragic situation does not lead to a satisfactory outcome. When the outcome is satisfactory, participants know what they must do next. They support the findings of the MCD and accept the situation as it is. Nevertheless, there is not always a sense of relief or closure. The treatment options may remain unclear, or the feeling of impotence may persist. Additional research might therefore examine what further support is needed and the extent to which it can be provided.

General discussion

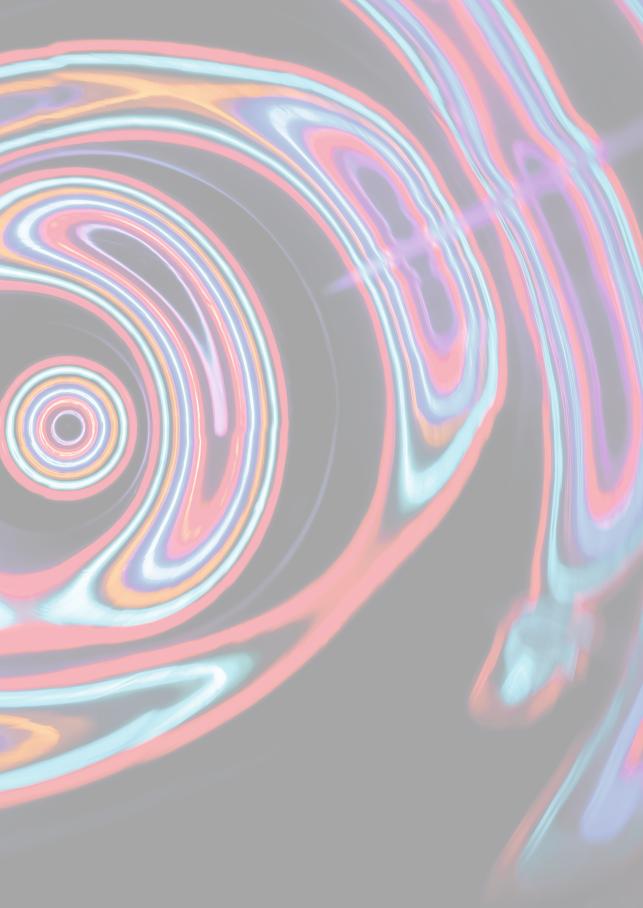
## Conclusion

In this study, we examined how healthcare professionals can be supported in dealing with tragic situations through MCD. In their daily professional practice, care providers are regularly confronted by tragedy. They must make choices between alternative actions, knowing that both options will cause some degree of harm to the patient and to others involved. This can cause feelings of powerlessness and confusion. Tragedy leaves no one unmoved. MCD can help care providers faced with a tragic situation to reflect on and discuss their experiences, by creating awareness of harm, acknowledging emotions and addressing worldview. This can promote the development of virtues, which enable professionals to find the right balance between acceptance and action, between emotional engagement and distance, and between awareness of existential depth and looking ahead to the future. Facilitators can support care providers in their search for balance by helping them to reflect on their experiences in tragic situations. In doing so, MCD can help to unlock the knowledge inherent in tragedy: knowledge about life itself and precisely what makes life valuable.

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# Appendices

## Summary

Moral case deliberation (MCD) is an intervention intended to support care providers in making the moral choices demanded by their work. During a moral case deliberation session, care providers jointly examine a moral question based on concrete experience, under the guidance of a trained facilitator. Various methods can be applied. One of the most widely used is the dilemma method, in which the moral question is formulated and examined as a dilemma. While attending a number of moral case deliberation sessions in the hospital, I was moved by the tragedy inherent in many of the cases raised. Patients are subjected to serious pain and suffering, often associated with a deterioration in their quality of life or impending death. In these situations, care providers are expected to make choices. They struggle to decide the best way forward. Whatever choice they make, they are unable to fully prevent negative outcomes. This has consequences not only for the patient, who must learn to accept that his life is now irrevocably damaged and is confronted by his own mortality, but also demands much of the care providers. They are responsible for the choices they make, none of which will have a completely positive outcome. What is needed if moral case deliberation is to be useful in this type of situation?

The objective of this study is to clarify how moral case deliberation works in tragic situations. The key question is therefore: How can healthcare professionals be supported in dealing with tragic situations through MCD? Many prior studies have focused on the aims, implementation methods and outcomes of moral case deliberation. The current study is unique in that it centres on the way in which moral case deliberation works and achieves results in the face of tragedy.

**Chapter 1** provides a general introduction, including definitions of the terms 'moral case deliberation' and 'tragedy' as used throughout the thesis. As noted above, moral case deliberation involves an interactive meeting during which care providers systematically reflect on a moral question drawn from concrete personal experience. The definition of 'tragedy' and 'tragic situations' applied in this research is based on the philosophical anthropology of Martha Nussbaum. Chapter 1 outlines her views on tragedy, with particular reference to the concepts of harm, emotion and worldview. Tragedy is related to the fragility of life. Nussbaum does not see tragedy in the unpredictable vicissitudes of life, the 'things that just happen', no matter how inconvenient or threatening they may be. Rather, she links tragedy with conscious choices. In this thesis, we focus on the choices that care providers must make as they support their patients. Here, tragedy refers to the fact that all available options will bring some degree of harm, whether in the form of pain, sorrow or frustration because the care provider is unable to safeguard some other interest. When faced with such choices, it is extremely difficult to determine what will contribute to 'the good life'.

The introduction concludes with our formulation of the research questions. The key research question is: How can healthcare professionals be supported in dealing with tragic situations through MCD? To clarify this, we must first conduct a reconnaissance of the field with which we are concerned. This gives rise to the first sub-question: How do MCD participants experience the support provided by MCD in dealing with a tragic situation? We then turn our attention to the facilitators. To gain a better understanding of the role of moral case deliberation, we draw upon their practical experience and knowledge. The second sub-question is therefore: How can facilitators support healthcare professionals in tragic situations, and assist them in dealing with issues related to harm, emotion and worldview?

To answer these sub-questions, we conducted semi-structured interviews with both participants and facilitators. The interview findings were then analysed using qualitative methods, focusing on the personal views and experiences of the respondents.

**Chapter 2** describes a study examining the experiences of participants in a moral case deliberation concerning a tragic case. How did they experience the element of tragedy, and how would they describe the role of the moral case deliberation process? The case in question concerned a pregnant woman who had been diagnosed with a terminal brain tumour. Despite the extremely poor prognosis, she wished to continue the pregnancy. The question facing care providers was whether they should administer antibiotics and/or parenteral nutrition (tube feeding) in order to prolong her life and improve the baby's chances of survival, or adopt a palliative regime. Three moral case deliberation sessions were devoted to this case, at which the dilemmas encountered by care providers were discussed in turn. Ten participants in these sessions agreed to share their experiences with us. For them, the tragic element was such that the case continues to occupy their minds. Although one would think that tragedy is likely to result in 'moral distress', there is a difference. In a case of moral distress, the most appropriate treatment option is clear but the care provider is prevented from following that course of action due to either internal or external reasons. In a tragic situation, there is no 'good' choice because both alternatives bring some degree of moral harm. In our study, we see that tragedy goes hand in hand with existential elements such as feelings of intense grief or sorrow, a confrontation with one's own powerlessness, or the erosion of human dignity. Moral case deliberation supports reflection on these aspects. Once the dilemma is formulated and the potential harm set out, it is clear that there are no simple solutions. The emphasis on seeking solutions based on ethical principles, as seen in ethics education, can distract from adopting a moral attitude which clearly demonstrates an acknowledgement of the dilemma. Moral case deliberation encourages interaction and offers a basis for the sharing of experiences. In this respect, it differs from psychological support. The focus of moral case deliberation is not the ability to process emotions, but is more concerned with creating insights and promoting a personal learning process. This case shows how the need to take action and the need to accept contingency come together. We conclude that the value of moral case deliberation can be further increased by reflection on this combination.

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In **Chapter 3** we examine the role of addressing harm during the moral case deliberation process, based on the experiences of facilitators. The concept of 'harm' applied here is based on Nussbaum, whereby harm refers to the moral damage that cannot be avoided nor rectified at a later date. What sets the choices to be made in a tragic situation apart is that no option is entirely devoid of harm, while it is also impossible to objectively determine which option will result in the least harm. There will always remain some fundamental moral harm, and this must be acknowledged.

During a moral case deliberation, participants reflect on dilemmas drawn from actual practice. One step in the reflection process is to describe the harm that is associated with a particular choice. We examine how facilitators regard the importance of addressing harm during the moral case deliberation, and how they support participants in reflecting on harm.

According to the facilitators, the added value of addressing harm during the process is that it raises awareness of tragedy. Formulating the harm reveals how care providers are personally affected by the issues at hand and what is at stake for them. In order to cope adequately with tragedy, it is essential to take time during the moral case deliberation to acknowledge the nature of the harm involved. Tragedy can give rise to feelings of guilt, since there will always be some harm. It is therefore important to distinguish between avoidable harm and unavoidable harm. The discussion of harm as part of moral case deliberation encourages participants to share experiences and brings them closer together.

Discussing harm can increase care providers' resilience. They learn to acknowledge and accept what cannot be changed, and they are encouraged to focus on the things that are within their power and ability. It is a question of finding an appropriate balance between acceptance and heroic measures. While discussing the various options, there are opportunities to examine treatment possibilities and underlying values in greater depth. This may reveal new ways in which to approach the dilemma, although this is not always the case. Care providers must be aware that the quest for a practicable middle road will not always be successful. Moral case deliberation can provide a means to reflect on the question of how to repair harm, if that is indeed possible. This ties in with the concept of 'moral repair'. The word 'repair' can inadvertently create the impression that everything in healthcare can be controlled. In tragic situations, however, there can be lasting harm which patients must learn to live with. Tragedy is an inherent part of our world and our existence. By no means all damage can be repaired. Formulating the potential harm not only reveals the fragility of life but encourages care providers to think about what they deem important in their care for vulnerable patients. It casts light on what makes life valuable and precious.

In **Chapter 4** we examine the facilitators' view on the role of emotions within moral case deliberation. The difficult choices that care providers face in tragic situations are likely to evoke emotions. During the moral case deliberation, care providers are invited to reflect on the moral aspects of the dilemma under consideration. Emotions are rarely explicitly addressed. This raises the question of what role emotions actually play in moral case deliberation.

According to facilitators, the role of emotions depends on the phase that the moral case deliberation process has reached. In the initial phase, emotions are an indicator of participants' engagement with the situation under discussion. During the reflection phase, when various aspects of the case are examined in more detail, emotions are likely to reveal the participants' values and personal beliefs. These values and beliefs underpin, and are an expression of, personal responsibility. In the final phase, emotions can indicate relief or gratitude. In some cases, there is no relief because no resolution can be found. Here, the moral case deliberation can help participants to share their burden.

One negative aspect of emotions is that they can hinder the discussion, or distract it from the moral question. It can then be useful to set emotions aside. A positive aspect is that emotions can clarify the dilemma and can inspire new insights. Facilitators therefore consider it important to devote time to exploring and acknowledging emotions. Inviting participants to reveal and discuss their emotions helps them to understand each other's perspectives. Emotions also play a part in 'moral imagination', the ability to apply values to a situation based on various perspectives, and in promoting the 'moral community', whereby everyone is involved in the deliberation and all views are taken into account. Facilitators state that this helps to enhance moral resilience. Devoting attention to emotions can therefore support responsible decision-making while also increasing the moral resilience of care providers.

In **Chapter 5** we look at the role of worldview in moral case deliberation. Once again, we draw upon the knowledge and experience of facilitators, examining how they address worldview during the moral case deliberation process. We define worldview as "fundamental beliefs about life, death and dying which structure ideas about how life events relate to each other." We have chosen this definition because it is broad and inviting enough to allow respondents to describe their own views and experiences. The results show that worldview plays both an explicit and an implicit role during moral case deliberation. The explicit role relates to the religious beliefs of patients and professionals. It requires both facilitators and participants to avoid stereotyping and to take various perspectives into consideration. Cultural and religious convictions influence our view of illness, suffering and dying, and determine how a moral issue is to be formulated. The implicit role comes to the fore when addressing core values, which indicate how participants view life. What makes life worth living? Reflection on these fundamental values is an important part of moral case deliberation in order to arrive at the heart of

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the dilemma. Worldview can be seen as the core of, and inspiration for, values. Including worldview in the discussion can help to create a common understanding within the group. Worldview also touches on the spiritual and existential dimensions of a case. It can, however, be difficult for facilitators to address the topic of worldview given its sensitive and personal nature and the difficulty of expressing certain aspects in words. Also, we live in a secular society in which increasing rationalization means that existential questions are regarded as a matter for private contemplation, not public discussion. It may be appropriate to devote explicit attention to worldview during the moral case deliberation process in order to clarify the fundamental character of values. However, the topic must be addressed with caution since participants tend to interpret worldview in terms of religious and personal beliefs rather than as an invitation to reflect on 'the good life' in the broadest sense.

In **Chapter 6** we answer our research questions and place the findings in a broader perspective. Tragedy is not only negative; by allowing us to experience fragility and vulnerability, it can reveal what we deem precious in life and what makes life worthwhile. Moral case deliberation can help care providers to reflect on a tragic situation. The essence is an exploration of important values. As noted in the previous three chapters, this occurs in three ways during the moral case deliberation process: through becoming aware of harm, through recognizing and devoting attention to emotions, and by addressing worldview. Each of these three themes includes specific areas of tension.

In the case of becoming aware of harm, a tension can be seen between the necessity of action on the one hand and the acceptance of things that cannot be changed on the other. Here, virtue ethics becomes relevant. Virtue ethics is not so much concerned with what we must or should do, but rather on who we are and how we can achieve personal development. The virtue is geared towards improving one's own attitude and behaviour, developing the habit to put normative principles into practice. For a healthcare professional, learning to deal with harm is a virtue that must indeed be practised. Moral case deliberation offers a good setting for this practice, and the facilitator can play an important part. If participants are too quick to move on to a discussion of the action to be taken, he or she must steer the conversation back to the issue of harm. The facilitator should encourage participants to identify and acknowledge potential harm. If the participants adopt too strong a focus on the inevitability of harm, he or she must ensure that this does not stifle the discussion and prevent action.

In terms of acknowledging emotions, there is a tension between engagement and distance. Participants must be allowed the opportunity to express their emotions but at the same time it is necessary to create a certain distance in order to open those emotions up to discussion and examination. This also involves the development of a virtue, namely the ability to strike an appropriate balance between surrendering to emotion and suppressing emotion. In this study, we note that the role of emotions within moral case

deliberation depends on the phase that has been reached. In the initial phase, emotions must be recognised. During the reflection phase, emotions are examined, while in the final phase participants consider how these emotions help to define what they regard as valuable in life. These phases overlap. The facilitator's task is to oversee the dynamic process whereby the role of emotions shifts according to phase.

The third area of tension relates to worldview. While emotions give some indication of values, worldview encapsulates values within a more comprehensive vision of 'the good life'. When addressing worldview, there is a tension between the realization of existential depth - there are sensitive issues at stake - and attention for action: what can actually be done. This requires the facilitator to seek a balance between slowing the discussion to seek greater depth, and steering the discussion towards the question of how participants can move towards deciding the appropriate course of action. Because various worldviews are likely to be represented, there can be different perspectives on the tragic situation. Through appropriate questioning, the facilitator must encourage participants to reveal their underlying values and visions, and the implications in terms of treatment and interaction with patient and family. Sharing their perspectives helps participants to clarify their thinking and adopt a broader horizon with regard to further options. Within the moral case deliberation, worldview is not abstract knowledge or conviction but is always connected to the practice and experience of care providers. Finding the right balance between existential depth and concrete action is once again a form of virtue and one that both the facilitator and participants will learn through practice.

The chapter concludes with a brief reflection on the methodology and the implications for practice and for future research. We recommend including moral case deliberation in training programmes for healthcare professionals and in the policy of healthcare institutions. We further recommend that attention should be devoted to the existential aspects of moral case deliberation. Lastly, we recommend that training for facilitators should include the opportunity to practise guiding professionals in discussing tragic situations. Further research should examine the role of tragedy in moral case deliberation from the patient's perspective, address harm, emotion, and worldview in the evaluation of moral case deliberation and investigate the need for other forms of clinical ethics support.

Our **conclusion** is that moral case deliberation can indeed support care providers who are faced with a tragic situation. Professionals must develop certain virtues to ensure that they become aware of harm, can acknowledge the role of emotions and are able to address worldview. This entails seeking an appropriate balance between acceptance and heroic measures, between emotional involvement and distance, and between the realization of existential depth and anticipation of future action. Facilitators can support care providers in finding this balance. Moral case deliberation can unlock the knowledge that is hidden within tragedy: knowledge about life itself and about everything from which life derives its value.

## Samenvatting

Moreel beraad is een interventie die erop gericht is zorgverleners te ondersteunen bij de morele keuzes waar ze in hun werk voor staan. In moreel beraad onderzoeken zorgverleners gezamenlijk een morele vraag aan de hand van een concrete ervaring en onder leiding van een daartoe opgeleide gespreksleider. Er kunnen verschillende methodes gehanteerd worden. Een veel gebruikte methode is de dilemma methode, waarin de morele vraag als dilemma wordt geformuleerd en onderzocht. Tijdens het bijwonen van een aantal moreel beraden in het ziekenhuis, werd ik geraakt door de tragiek van ingebrachte casuïstiek. Patiënten worden getroffen door ernstig lijden, vaak gekoppeld aan een beperking van kwaliteit van leven of een naderend overlijden. Van zorgverleners worden in deze situaties keuzes verwacht, waarbij ze worstelen wat ze moeten doen. Welke keuze ze ook maken, ze kunnen negatieve uitkomsten niet helemaal voorkomen. Dit heeft niet alleen gevolgen voor de patiënt, die moet leren leven met leven dat beschadigd is en blijft, met onherroepelijkheid en sterfelijkheid, maar vraagt ook veel van de zorgverlener. Zij zijn verantwoordelijk voor hun keuzes, die hoe dan ook schaduwzijden hebben. Als moreel beraad in deze situaties van tragiek wil helpen, wat is dan nodig?

Doel van de studie is te verhelderen hoe moreel beraad werkt in situaties van tragiek. De vraag die in deze thesis centraal staat is: Hoe kunnen zorgprofessionals worden ondersteund in het omgaan met tragische situaties via moreel beraad? Veel studies naar moreel beraad betreffen doelen, wijze van implementatie en uitkomsten. Uniek aan deze studie is dat het gaat om een onderzoek naar de werking van moreel beraad bij tragiek.

**Hoofdstuk 1** biedt een algemene inleiding. Hier introduceren we de begrippen moreel beraad en tragiek. Een moreel beraad is, zoals hierboven aangegeven, een interactieve bijeenkomst waarin zorgverleners systematisch reflecteren op een morele vraag die voortkomt uit een concrete persoonlijke ervaring. Voor het begrip tragiek sluiten we aan bij de wijsgerige antropologie van Nussbaum. We schetsen haar gedachtengoed over tragiek, met specifieke aandacht voor de concepten schade, emoties en levensbeschouwing. Tragiek is gerelateerd aan de kwetsbaarheid van het leven. Nussbaum ziet tragiek niet in de wisselvalligheden in het bestaan, hoe bedreigend deze ook kunnen zijn. Ze verbindt tragiek aan het maken van bewuste keuzes. In deze thesis richten we ons op de keuzes waar zorgverleners voor staan in hun begeleiding en zorg voor patiënten. Tragiek houdt in dat er bij ieder van de voorliggende handelingsopties in het dilemma schade blijft in de vorm van pijn, verdriet of frustratie over het andere belang dat de zorgverlener niet kan vervullen. Het is in deze keuzes uiterst moeilijk om te bepalen wat bijdraagt aan het goede leven.

De inleiding wordt besloten met het formuleren van de onderzoeksvragen. De centrale onderzoeksvraag luidt: Hoe kunnen zorgprofessionals worden ondersteund in het omgaan met tragische situaties via moreel beraad? Om dit te kunnen verhelderen is allereerst nodig dat we het veld verkennen waar we over spreken. Hierover gaat de eerste deelvraag: Hoe ervaren deelnemers de ondersteuning door moreel beraad in het omgaan met een tragische situatie? Daarna richten we onze aandacht op de gespreksleiders. Om meer inzicht te krijgen in de rol van moreel beraad maken we gebruik van hun expertise en kennis vanuit de praktijk. De tweede deelvraag is: Hoe kunnen gespreksleiders zorgprofessionals ondersteunen in tragische situaties en hen helpen omgaan met kwesties die verband houden met schade, emotie en levensbeschouwing?

Om deze deelvragen te beantwoorden hebben we semigestructureerde interviews gehouden met deelnemers en gespreksleiders moreel beraad. De interviews zijn geanalyseerd met kwalitatieve methoden, waarin de visies en ervaringen van deelnemers en gespreksleiders centraal stonden.

Hoofdstuk 2 beschrijft een onderzoek naar de ervaringen van deelnemers aan een moreel beraad over een tragische casus. Hoe werd de tragiek ervaren door de deelnemers en wat is de rol van het moreel beraad geweest? De casus betreft een zwangere vrouw met een dodelijke hersentumor. Ondanks de uiterst slechte prognose, wil ze de zwangerschap behouden. De vraag die voorligt is of zorgverleners de vrouw moeten behandelen met een sondevoeding/antibiotica om haar leven te verlengen en de vooruitzichten voor het kind te verbeteren, of dat ze de behandeling moeten richten op comfort en palliatieve zorg. Over deze casus is een drietal moreel beraden gehouden, waarin de dilemma's die zorgverleners achtereenvolgens tegenkwamen in de zorg voor deze vrouw, werden besproken. Tien zorgverleners, die betrokken waren bij de behandeling en die de moreel beraden hebben bijgewoond, wilden hun ervaringen met ons delen. Wat tragiek voor hun kenmerkt, is dat de casus bijblijft. Hoewel tragiek hierin doet denken aan morele distress, is er een verschil. Bij morele distress is de juiste handeling bekend, maar wordt de zorgverlener door interne of externe redenen verhinderd om overeenkomstig te handelen. Bij tragiek is er geen goede keuze omdat beide alternatieven met morele schade gepaard gaan. We zien in dit onderzoek dat tragiek gepaard gaat met existentiële elementen, zoals de ervaring van intens verdriet, de confrontatie met machteloosheid en de bedreiging van menselijke waardigheid. Moreel beraad helpt bij de reflectie op deze elementen. Het formuleren van het dilemma en het expliciteren van schade maken duidelijk dat er geen eenvoudige oplossing is. De nadruk op het zoeken naar oplossingen op basis van ethische principes, zoals we die tegen kunnen komen in ethiekonderwijs, kan afleiden van het innemen van een morele houding die getuigt van erkenning van het dilemma. Moreel beraad stimuleert wederzijdse interactie en biedt een basis om ervaringen te delen. Het verschilt hierbij van psychologische ondersteuning. De focus van moreel beraad ligt niet op het omgaan met emoties op zich, maar staat in het kader van het vormen van inzicht en het entameren van een persoonlijke leerproces. Deze casus laat zien hoe in een tragische situatie het moeten handelen en het moeten aanvaarden van contingentie samenkomen. We concluderen dat de waarde van moreel beraad vergroot kan worden door reflectie op deze combinatie.

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In **Hoofdstuk 3** onderzoeken we de rol van het adresseren van schade in moreel beraad in de ervaring van gespreksleiders. In ons concept van schade volgen we Nussbaum. Schade betreft de morele schade die niet vermeden kan worden of kan worden opgelost. Wat keuzes in een tragische situatie bijzonder maken, is dat deze niet zonder schade mogelijk zijn en dat niet objectief vastgesteld kan worden welke optie de geringste schade biedt. Er blijft een fundamentele morele schade aanwezig, die moet worden erkend.

In moreel beraad reflecteren deelnemers op deze dilemma's uit de zorgpraktijk. Een stap in het reflectieproces is het expliciteren van de schade die gepaard gaat met de keuze. We onderzoeken hoe gespreksleiders het belang van het adresseren van schade in moreel beraad ervaren en hoe ze deelnemers ondersteunen in het reflecteren op schade.

Toegevoegde waarde van het adresseren van schade in moreel beraad ligt volgens gespreksleiders in bewustwording van tragiek. Het formuleren van schade toont hoe zorgverleners geraakt worden door de kwestie en wat er voor de zorgverleners op het spel staat. Voor het omgaan met tragiek is belangrijk in moreel beraad de tijd te nemen om de aard van de schade te erkennen. Tragiek kan gepaard gaan met gevoelens van schuld, omdat schade bij tragiek blijft bestaan. Het is daarbij van belang te onderscheiden tussen vermijdbare en onvermijdbare schade. Het bespreken van schade in moreel beraad draagt bij aan het samen delen van ervaringen en verbindt de deelnemers met elkaar.

Het bespreken van schade kan weerbaarheid van zorgverleners vergroten door enerzijds te erkennen wat niet veranderd kan worden, en anderzijds aandacht te besteden aan wat wel in hun macht ligt. Het gaat erom de balans te vinden tussen aanvaarding en handelen. Tijdens het afwegen van de verschillende opties in het dilemma kunnen handelingsmogelijkheden en onderliggende waarden worden onderzocht. Dit kan nieuwe mogelijkheden openen om met het dilemma om te gaan, maar niet altijd. Zorgverleners moeten zich er van bewust zijn dat het zoeken naar een begaanbare middenweg niet altijd lukt. Moreel beraad kan ertoe bijdragen om te reflecteren op de vraag hoe schade te repareren waar mogelijk. Dit sluit aan bij de notie van 'moral repair'. Het woord repareren kan onbedoeld de indruk wekken dat alles in de gezondheidszorg gecontroleerd kan worden. Maar in tragische situaties kan er blijvende schade zijn waar patiënten mee moeten leren leven. Uiteindelijk maakt tragiek deel uit van onze wereld en ons bestaan en is nooit alle schade op te lossen. Het formuleren van schade laat niet alleen de kwetsbaarheid van het leven zien, maar laat zorgverleners ook nadenken over wat zij belangrijk vinden in hun zorg voor kwetsbare patiënten. Daarmee biedt het zicht op wat het leven waardevol en kostbaar maakt.

In **Hoofdstuk 4** gaan we in op de visie van gespreksleiders op de rol van emoties in moreel beraad. De moeilijke keuzes waar zorgverleners voor staan in tragische situaties, brengen

emoties met zich mee. In moreel beraad worden zorgverleners uitgenodigd te reflecteren op morele aspecten van het dilemma dat voorligt. Emoties worden doorgaans niet expliciet geadresseerd. Dit roept de vraag op welke rol emoties in moreel beraad spelen.

Volgens gespreksleiders hangt de rol van emoties af van de fase waar moreel beraad zich in bevindt. In de initiële fase zijn emoties een signaal van de bezorgdheid van deelnemers aangaande de situatie. Tijdens het proces van het onderzoeken van de casus in de reflectie fase geven emoties inzicht in waarden en overtuigingen van de deelnemers, en zijn ze een uitdrukking van verantwoordelijkheid. In de concluderende fase kan er sprake zijn van opluchting en dankbaarheid of kan juist een gebrek aan opluchting worden ervaren. Wanneer opluchting niet tot stand komt, kan moreel beraad helpen de last te delen.

Een negatief aspect van emoties is dat ze het gesprek kunnen blokkeren of moreel beraad kunnen afleiden van de morele vraag. Het parkeren van emoties kan dan nuttig zijn. Een positief aspect is dat ze het dilemma kunnen verhelderen en een bron kunnen zijn van nieuwe inzichten. Gespreksleiders vinden het dan ook belangrijk tijd te nemen om emoties te verkennen en te erkennen. Het naar voren laten komen en bespreken van emoties kan deelnemers helpen zich in de verschillende perspectieven te verplaatsen. Emoties dragen bij aan morele verbeelding, de mogelijkheid om vanuit verschillende perspectieven waarden toe te passen op een situatie, en morele gemeenschap, waarin iedereen bij de deliberatie betrokken wordt. Dit draagt volgens gespreksleiders bij aan morele weerbaarheid. Aandacht schenken aan emoties kan daardoor bijdragen aan het maken van verantwoordelijke keuzes en morele weerbaarheid van zorgverleners vergroten.

In Hoofdstuk 5 nemen we de rol van levensbeschouwing in moreel beraad onder de loep. Ook in dit hoofdstuk richten we ons op de ervaring van gespreksleiders. We onderzoeken hoe gespreksleiders levensbeschouwing adresseren in moreel beraad. We definiëren levensbeschouwing als 'fundamentele overtuigingen over leven, dood en lijden die ideeën structureren over hoe levensgebeurtenissen met elkaar samenhangen'. We kiezen voor deze definitie omdat deze breed en uitnodigend is voor onze respondenten om te vertellen over hun visies en ervaringen. De resultaten laten zien dat levensbeschouwing een expliciete en impliciete rol speelt tijdens moreel beraad. De expliciete rol betreft de religieuze overtuigingen van patiënten en professionals. Dit vraagt van gespreksleiders en deelnemers om het vermijden van stereotypering en het aandacht schenken aan verschillende perspectieven. Culturele en religieuze visies bepalen hoe we tegen lijden, ziekte en dood aankijken en hoe een moreel issue wordt geformuleerd. De impliciete rol komt naar voren in het adresseren van kernwaarden, die aangeven hoe deelnemers tegen het leven aankijken. Wat maakt het leven waard om geleefd te worden? Bezinning op deze fundamentele waarden is van belang om in moreel beraad tot de kern van het dilemma te komen. Levensbeschouwing kan gezien worden als de binnenkant en inspiratie van waarden. Moreel beraad kan door levensbeschouwing bespreekbaar te maken, bijdragen aan onderlinge verbinding en raken aan de spirituele en existentiële

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dimensie van een casus. Het kan lastig zijn voor gespreksleiders om dit in moreel beraad naar voren te laten komen, gezien het gevoelige karakter dat er mee gemoeid kan zijn voor deelnemers, en de moeite om er woorden voor te vinden. Hierbij speelt mee dat de samenleving is geseculariseerd en dat existentiële vragen door toenemende rationalisatie beschouwd worden als behorend tot de privésfeer. Om het fundamentele karakter van waarden te verhelderen, kan meer expliciete aandacht voor levensbeschouwing zinvol zijn gedurende moreel beraad. Levensbeschouwing moet echter met voorzichtigheid worden aangekaart, omdat het door deelnemers gemakkelijk geïnterpreteerd wordt in termen van religieuze en persoonlijke overtuigingen, meer dan als uitnodiging om te reflecteren op het goede leven in zijn geheel.

In **Hoofdstuk 6** worden onze onderzoeksvragen beantwoord en worden bevindingen in een breder perspectief geplaatst. Tragiek is niet alleen negatief; in de ervaring van kwetsbaarheid en fragiliteit, kan het onthullen wat we waardevol vinden in het leven en wat het leven de moeite waard maakt. Moreel beraad kan zorgverleners helpen te reflecteren op een tragische situatie. Het gaat daarbij om een oriëntatie op belangrijke waarden. Dit gebeurt in moreel beraad, zoals in de vorige hoofdstukken besproken, op drie manieren: door de bewustwording van schade, in het omgaan met emoties en het adresseren van levensbeschouwing. In elk van deze drie thema's ligt een spanningsveld besloten.

Bij bewustwording van schade kan een spanning gezien worden tussen het moeten handelen enerzijds en het accepteren van wat niet veranderd kan worden anderzijds. De deugdethiek is hierbij van belang. De deugdethiek richt zich niet zozeer op wat we moeten doen, maar eerder op hoe we ons kunnen vormen. Deugdzaamheid is een gerichtheid op de verbetering van de eigen houding en gedrag, de bereidheid om ons daarin te oefenen. Het leren omgaan met schade als professional is een deugd die geoefend moet worden. Moreel beraad biedt een plek voor deze oefening. De gespreksleider kan hierbij een belangrijke rol spelen. Richten de deelnemers zich te snel op het handelen in het dilemma, dan moet hij aansturen op het benoemen en erkennen van schade. Focussen de deelnemers te zeer op de onvermijdelijkheid van schade, dan is het zaak ervoor te zorgen dat dit niet leidt tot verlamming.

In het erkennen van emoties is er sprake van een spanningsveld tussen betrokkenheid en afstand. Aan de ene kant moet ruimte worden geboden aan het uiten van emoties, maar aan de andere kant moet er ook afstand gecreëerd worden om emoties bespreekbaar te maken en te kunnen onderzoeken. Ook hier gaat het om de ontwikkeling van een deugd, namelijk het vinden van het juiste midden tussen het zich overgeven aan emotie en het verdringen ervan. In ons onderzoek kwam naar voren dat er verschillende fasen zijn in de rol die emoties spelen in moreel beraad: de initiële fase waarin het gaat om ruimte bieden aan een emotie, de reflectiefase waarin de emotie onderzocht wordt en de concluderende fase, waarin wordt vastgesteld hoe het onderzoek van de emotie bijdraagt aan inzicht in wat in het leven van waarde is. De fases lopen in elkaar over. Taak van de facilitator is om dit dynamische proces van de emoties in relatie tot de fases waarin zij voorkomen te bewaken.

Het derde spanningsveld betreft levensbeschouwing. Waar emoties zicht geven op waarden, staan bij levensbeschouwing deze waarden in een meer omvattende visie op het goede leven. Bij het adresseren van levensbeschouwing is sprake van een spanning tussen het besef van existentiële diepte – het gaat om wezenlijke vraagstukken - en aandacht voor actie: datgene wat daadwerkelijk gedaan kan worden. Voor de gespreksleider betekent dit het zoeken naar een balans tussen het vertragen en verdiepen van het gesprek en het sturen van het gesprek richting de vraag hoe de deelnemers verder kunnen komen en moeten handelen. Door uiteenlopende levensbeschouwingen zijn er verschillende perspectieven op de tragische situatie mogelijk. Het is de taak van de gespreksleider om in het gesprek door te vragen naar onderliggende waarden en visies op wat dit betekent voor de behandeling en omgang met patiënt en familie. Uitwisseling van de verschillende visies draagt eraan bij het denken en handelen helder te krijgen en te verruimen. Levensbeschouwing in moreel beraad is geen abstracte kennis of overtuiging, maar is altijd verbonden met de praktijk en ervaringen van zorgverleners. Dit zoeken naar balans tussen existentiële diepte en daadwerkelijk handelen is opnieuw een vorm van deugd, die de gespreksleider en deelnemers leren door oefening.

Dit hoofdstuk sluit af met een korte reflectie op de methodologie en implicaties voor praktijk en toekomstig onderzoek. We adviseren om moreel beraad op te nemen in de opleiding van zorgprofessionals en in beleid van zorginstellingen. Daarnaast adviseren we om aandacht te besteden aan de existentiële aspecten in moreel beraad. Tenslotte adviseren we om het begeleiden van zorgprofessionals in het gesprek over tragische situaties te oefenen in de opleiding tot gespreksleider. Verder onderzoek is nodig naar de rol van tragiek in moreel beraad volgens patiënten, naar schade, emotie en levensbeschouwing in de evaluatie van moreel beraad en naar de behoefte aan andere vormen van klinische ethiek ondersteuning.

Onze **conclusie** is dat een moreel beraad zorgverleners die met een tragische situatie te maken hebben, kan ondersteunen. Het bewust worden van schade, het erkennen van emoties en het adresseren van levensbeschouwing vraagt van zorgprofessionals het ontwikkelen van deugden. Daarbij gaat het om het zoeken naar de juiste balans tussen aanvaarding en handelen, tussen emotionele betrokkenheid en afstand, en tussen besef van existentiële diepte en vooruit kijken naar wat gedaan kan worden. Gespreksleiders kunnen zorgverleners bij het zoeken naar deze balans ondersteunen. Moreel beraad kan zodoende helpen kennis te ontsluiten die in tragiek verscholen ligt: kennis over het leven zelf en dat wat daarin van waarde is.

# About the author

Benita Spronk was born in 1960 in Zaandam, the Netherlands. She studied Theology at the Vrije Universiteit Amsterdam (VU) finishing her doctoral degree in 1987, with a major in Ethics and a minor in Philosophy of Religion.

Combining her interest in existential questions and ethics, she started her career as a spiritual counselor, at first on a voluntary basis at the Andreas Hospital in Amsterdam, followed by a temporary assignment at the Institute for Epilepsy Treatment in Heemstede. In 1991, she got her tenure at the Medical Center Haaglanden (MCH). Besides her work at MCH she was a freelance teacher of ethics at the Training center for ICU nurses and a teacher of ethics and social interaction at the Regional training center for surgical assistants in The Hague. To develop her skills as a spiritual counselor she attended the post-doctoral Clinical Pastoral Training in 1995. She was Chair of the MCH Ethics Committee (1995-2007) and a member of the MCH Medical Ethics Review Committee (2004-2007). During this period she was focused on topics such as evaluation of euthanasia policy/palliative sedation, withholding life-sustaining treatment and the defining of a code of conduct. She wrote 'Gezond verstand: hoe kom ik tot een medisch ethisch antwoord?' [Common sense: How do I acquire a medical-ethical point of view?] about her experiences, which was published by Ten Have Publishers, in 1997.

From 2006 she combined her position as a spiritual counselor at MCH with a position at VUmc, before making the full switch the following year. In 2013, she became Head of the Department of Spiritual Care. In 2021 she was appointed as Head of the Department of Spiritual Care at both locations of Amsterdam University Medical Centers. In addition, she was editor of the Journal of Spiritual Care in the section 'Theoretical reflection, scientific articles & new talent (2008-2013) and a member of the Education Committee of the SKGV (Quality Register Spiritual Caregivers) (2012/13). She remained committed to ethics at Amsterdam University Medical Centers, first as a member and later as Chair of the Ethics Committee (2013-2022).

In 2010, the first contact with the Department of Ethics, Law and Humanities at Amsterdam University Medical Centers was established. Benita followed the abbreviated course as facilitator Moral Case Deliberation, supplemented with intervision meetings. This led to the start of her PhD study on the role of moral case deliberation in tragic situations, under the direction of prof. dr. Guy Widdershoven and prof. dr. Hans Alma.

Benita is married to Hans van Drongelen. They have two daughters, Julika and Milena.

CV en dankwoord

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Moral case deliberation is an intervention intended to support care providers in making the moral choices demanded by their work. During a moral case deliberation session, care providers jointly examine a moral question based on concrete experience, under the guidance of a trained facilitator. Various methods can be applied. In tragic situations, care providers struggle to decide the best way forward. Whatever choice they make, they are unable to fully prevent negative outcomes.

In this dissertation we investigate how participants experience the support provided by moral case deliberation in dealing with a tragic situation. Secondly we investigate the views and experiences of facilitators regarding three aspects of addressing tragedy in moral case deliberation, namely harm, emotions and worldview.