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VIEWPOINT

How Moral Case Deliberation Supports Good Clinical Decision MakingGiulia Inguaggiato, MPhil, Suzanne Metselaar, PhD, Bert Molewijk, PhD, and Guy
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Abstract

In clinical decision making, facts are presented and discussed, preferably in the context of both evidence-based medicine and patients' values. Because clinicians' values also have a role in determining the best courses of action, we argue that reflecting on both patients' and professionals' values fosters good clinical decision making, particularly in situations of moral uncertainty. Moral case deliberation, a form of clinical ethics support, can help elucidate stakeholders' values and how they influence interpretation of facts. This article demonstrates how this approach can help clarify values and contribute to good clinical decision making through a case example.

Values in Decision Making

Values can be thought of as "the essential *texturing* of everything we perceive, believe and aim for." Values inform our views of how things ought to be and guide us—either implicitly or explicitly—when difficult choices need to be made. ^{2,3} Clinical decision making is not any different. Decision science, which focuses on how the best scientific evidence can inform decisions and how to deal with <u>bias</u> and confounding factors in decision making, ^{4,5} can help render patients' and clinicians' values explicit and mobilize them in clinical decision–making processes. In this article, we argue that stakeholders making their values explicit and exploring them together can set the conditions for a more informed and morally sensitive decision–making process, especially in situations in which there is a lot at stake and the right thing to do is not that obvious for everyone involved. ⁶

We maintain that the use of moral case deliberation (MCD) supports a clinical ethics process of elucidating and exploring both values and facts and promoting the inclusion of the values of all those involved in considering what to do so as to promote morally informed clinical decision making. ^{7,8,9,10,11} This approach is particularly valuable in situations of moral uncertainty, ie, in cases in which there is disagreement among stakeholders about what should be done or when there is doubt about the right thing to do.

Facts and Values in Decision Making

Although the best available evidence and clinical experience are fundamental for good clinical decision making, they do not provide a sufficient basis for deciding what to do in any particular situation. ¹² Eliciting and weighing stakeholders' values—particularly, patients' and family members' values and preferences—is essential to good clinical decision making. ^{13,14} However, the <u>values of clinicians</u> should also be explicitly taken into account in good clinical decision making because the selection, interpretation, and communication of clinical facts and the evaluation of the clinical situation are always mediated by clinicians' normative assumptions about what is important or worth striving for in the situation at hand. ⁶ For instance, in end-of-life decisions, a physician's proposal of palliative care will be influenced by the meaning that he or she attributes to persistent pain and to a "good" death; both considerations express a normative stance on the relationship between quality of life and survival.

One way for a clinical team to explore values or normative assumptions and how they influence the experience of a clinical situation and motivate a decision for a certain course of action is MCD, a structured dialogue among members of a multidisciplinary group of health care professionals (eg, nurses, physicians, physiotherapists) about a difficult situation in which stakeholders experience moral disagreement or uncertainty. Dialogue and ethical reflection are guided by a trained MCD facilitator who uses a specific conversation method, such as the dilemma method. By means of a joint exploration of stakeholders' perspectives, participants come to a better understanding of a disagreement or the uncertainty within a situation, along with relevant values. After stakeholders' values have been explored, participants express their own views about which values are most important, investigate similarities and differences among stakeholders' values, and listen to each other's arguments. This process can lead to a joint solution, compromise, or better understanding of various positions. Results and insights from an MCD session support decision making by those who have formal decision—making responsibility.

During MCD meetings, scientific facts are also important, as disagreement and uncertainty can come from a lack of information or misunderstanding of available scientific evidence. Yet disagreements can also be due to differences in values and in how the facts of the situation are valued. By focusing on how values influence the ways in which stakeholders view a situation and its facts, differences in normative presuppositions of participants can be explored and the most relevant values prioritized.

Moral Case Deliberation

MCD differs from <u>shared decision making</u> in several respects. In contrast to shared decision making, in which the values of the patient or family members and the caregiver are explored to arrive at a patient-centered decision, MCD focuses on dealing with ethical dilemmas and deepening understanding of situations involving moral uncertainty.

Although mutual understanding and consensus might be achieved by exploring different values and perspectives, reaching a shared decision is not the primary aim of MCD. Furthermore, in most cases, deliberation takes place not between patient and treating physician but among caregivers in an interprofessional context. Deliberation aims to elucidate values and consider courses of action that follow from them, but a treating physician remains in charge and responsible for the decision–making process—in contrast to shared decision making, in which a physician shares this responsibility with a patient.

Dialogue plays a fundamental role in MCD. By engaging in dialogue, participants postpone first judgments and investigate their views and assumptions in a joint learning process. The purpose is not to convince others of a particular view but to foster exchange of perspectives and establish deeper understanding of the situation.¹⁵

In MCD, both facts and values are addressed. First, in order to clarify facts in an ethical dilemma, factual questions—which might address not only clinical knowledge and scientific evidence, but also how a situation relates to a patient's history and options—are posed. After factual questions have been considered, participants are asked to make all stakeholders' values explicit. Although the patient and family generally will not be present, their views and values can be elucidated by professionals involved in the case (eg, physicians, nurses). Of course, making values explicit requires accurate interpretation and a joint endeavor, as all participants contribute to the elaboration of values important to each stakeholder. Through this process, values are made concrete and translated into norms for action.

This process also shows how values influence the understanding of facts and suggest possible courses of action. After elucidating stakeholders' values, MCD participants are each asked to formulate what they consider to be the right action, what value is behind their choice, and how this value relates to the facts of the situation at hand. The participants' individual judgments are further explored through continued collaborative dialogue that enables a richer, collective understanding of the case—one that can account for various perspectives, including those of patient and physician. This process might result in consensus or at least foster acknowledgement of and openness to a plurality of views. In either case, a basis may be created for improving decision making in morally difficult situations.

Case

To illustrate MCD, we present a case example in which deliberation was led by one of the authors (G.W.) who, in his capacity as an ethics consultant, was asked by neonatal intensive care unit (NICU) staff to provide ethics support. A baby born at 40 weeks had been admitted to the NICU. The child suffered from congenital ichthyosiform erythroderma, and both parents were familiar with the TGM 1 mutation which caused

this condition. Newborns affected by this genetic condition are encased in a collodion membrane, which cracks before or after birth and takes 2-to-4 weeks to peel off. During this period, there is a high risk of infection. After this period, however, the skin of the baby is neither expected to require further (intensive) medical treatment nor to pose a direct risk to the child's health. ¹⁶

In accordance with standard procedure, the baby was treated with Vaseline (every 3 hours) and an anti-infective agent (every 12 hours), which necessitated changing bandages every 3 hours. The baby received maximum pain medication but cried heavily when nurses removed bandages. The care team, including physicians and nurses, was unsure how to respond. Should the baby's pain and crying be accepted as merely temporary? Or should the baby be sedated? Sedation is a common practice in the NICU¹⁷; babies are often treated while sedated, and sedation is stopped when it is no longer needed.

An MCD was organized to reflect on this difficult situation. During the MCD, it became clear that participants had different understandings of the situation influenced by what they valued most. On the one hand, nurses emphasized that the baby was seriously ill and suffering. Their core value was comfort, and accordingly they deemed it important that the baby's suffering be diminished. Therefore, they considered sedation to be the morally best option. On the other hand, the treating physician regarded the baby as healthy relative to other babies in the NICU since he was full-grown and could breathe on his own. She argued that sedation would imply ventilator support, which would come with infection risk, hinder lung development, and prevent the baby from interacting with the environment and people around him, temporarily inhibiting his social development. Her core value was noninterference, and she thus regarded enduring the situation as the morally best way to handle it.

Interestingly, the facts of the situation were not questioned: the nurses knew that sedating the baby would risk iatrogenic harm, and the physician knew that, without sedation, the baby's suffering could not be relieved. They did, however, value the facts differently. For the nurses, relieving pain was more important than risking harm; for the physician, abstaining from interfering with the baby's physical and social functioning was more important than relieving suffering. The nurses' and the physician's value-laden perceptions are also evident in their descriptions of the baby as ill or healthy. The nurses regarded the baby as seriously ill; the physician regarded the baby as relatively healthy compared to other babies on the ward, who needed ventilator support to survive.

During reflective dialogue, participants' perspectives became explicit and were jointly explored. It became clear to participants that they were motivated by different values that influenced their judgments about what to do. Acknowledging these differences enabled team members to understand each other better and search for consensus. The

nurses, understanding the priority placed by the physician on uninhibited development, acknowledged the value of not interfering with physiological and social functioning by offering sedation. The physician, understanding the nurses' concerns about the baby's suffering, recognized the nurses' distress. Both parties came to appreciate how behavior that seems to indicate illness (crying out of pain) can be regarded as a sign of health (being able to breathe and express emotions). As the baby's condition was expected to last only a limited period of time, all members of the team agreed that it was right to refrain from sedation and to continue treatment. In addition, to reduce the nurses' distress, their shifts were changed so that each provided care to the baby for a shorter period of time. When this plan was proposed and explained to the parents, they agreed.

Conclusion

Decision science focuses primarily on how to make decisions based on (clinical) facts and how to avoid bias and confounding factors in decision making. Less attention, however, is paid to ways in which patients' and clinicians' values influence decision making, how to make these values explicit, and how to deal with them in decision making processes. We have argued that clinical team members exploring values together in a methodical and structured way can support informed and sensitive decision-making processes, especially in high-stake situations of moral uncertainty or disagreement. MCD contributes to good clinical decision making by focusing on questions such as "'Why do we think it is important to act in a certain way?'... 'What values are behind our inclinations and intuitions?,' 'What values may be relevant to other stakeholders,' and 'how can we take them into consideration?'" By focusing on these questions, MCD offers a way to integrate values with facts in clinical decision making.

References

- 1. Kelly MP, Heath I, Howick J, Greenhalgh T. The importance of values in evidence-based medicine. *BMC Med Ethics*. 2015;16(1):2.
- 2. Nussbaum M. *Upheavals of Thought: The Intelligence of Emotions*. Cambridge, UK: Cambridge University Press; 2001.
- 3. Parker M. *Ethical Problems and Genetics Practice*. Cambridge, UK: Cambridge University Press; 2012.
- 4. Blumenthal-Barby J. Biases and heuristics in decision making and their impact on autonomy. *AJOB*. 2016;16(5):5-15.
- 5. Saposnik G, Redelmeier D, Ruff CC, Tobler PN. Cognitive biases associated with medical decisions: a systematic review. *BMC Med Inform Decis Mak*. 2016;16(1):138.
- 6. Molewijk AC, Stiggelbout AM, Otten W, Dupuis HM, Kievit J. Implicit normativity in evidence-based medicine: a plea for integrated empirical ethics research. *Heal Care Anal.* 2003;11(1):69-92.

- 7. Inguaggiato G, Metselaar S, Porz G, Widdershoven G. A pragmatist approach to clinical ethics support: overcoming the perils of ethical pluralism. *Med Health Care Philos*. 2019;22(3):427-438.
- 8. Stolper M, Molewijk B, Widdershoven G. Bioethics education in clinical settings: theory and practice of the dilemma method of moral case deliberation. *BMC Med Ethics*. 2016;17(1):45.
- 9. Weidema FC, Molewijk BAC, Kamsteeg F, Widdershoven GAM. Aims and harvest of moral case deliberation. *Nurs Ethics*. 2013;20(6):617-631.
- 10. Molewijk B, Kleinlugtenbelt D, Pugh SM, Widdershoven G. Emotions and clinical ethics support. A moral inquiry into emotions in moral case deliberation. *HEC Forum.* 2011;23(4):257-268.
- 11. Metselaar S, Molewijk B, Widdershoven G. Beyond recommendation and mediation: moral case deliberation as moral learning in dialogue. *Am J Bioeth*. 2015;15(1):50-51.
- 12. Tonelli MR. The philosophical limits of evidence-based medicine. *Acad Med.* 1998;73(12):1234-1240.
- 13. Fulford KWM. The value of evidence and evidence of values: bringing together values-based and evidence-based practice in policy and service development in mental health. *J Eval Clin Pract.* 2011;17(5):976–987.
- 14. Marzorati C, Pravettoni G. Value as the key concept in the health care system: how it has influenced medical practice and clinical decision-making processes. *J Multidiscip Healthc.* 2017;10:101-106.
- 15. Gadamer HG. *Truth and Method*. New York, NY: Continuum; 1997.
- 16. Craiglow BG. Ichthyosis in the newborn. *Semin Perinatol.* 2013;37(1):26-31.
- 17. McPherson C. Sedation and analgesia in mechanically ventilated preterm neonates: continue standard of care or experiment? *J Pediatr Pharmacol Ther*. 2012;17(4):351-364.
- 18. Stolper M, Metselaar S, Molewijk B, Widdershoven G. Moral case deliberation in an academic hospital in the Netherlands. Tensions between theory and practice. *J Int Bioethique*. 2012;23(3-4):60.

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