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Patient Participation in Clinical Ethics Interventions: A Requirement of Procedural and Epistemic Justice

Marleen Eijkholt, *Bioethics*, 2026.¹

Short summary

This article sets out to demonstrate the importance of patient participation (PP) in clinical ethics consultations. The author argues that the absence of PP in clinical ethics interventions (CEI) jeopardizes procedural and epistemic justice. They provide four cases to exemplify the risk of injustice involved to the patient when health care teams are not involving them or their SDM in CEI pertaining to their care.

Introduction

PP in CEI is common in the United States but not in Europe or Oceania. Outside the United States, CEI would most often not involve the patient, and the process of shared decision-making does not necessarily include CEI. PP in CEI may be common practice in a specific city or regions of a country, while it is the exception rather than the rule in other areas. Eijkholt argues that to ensure procedural and epistemic justice in CEIs, it is necessary to ensure that policies and standards enable involvement of patients or their SDM in clinical ethics consultation when the consultation pertains directly to the patient's care.

Key Points:

Procedural justice refers to the patient's right to know about a CEI pertaining to their care, as well as their right to be heard. It includes the patient's right to contribute and be informed about the knowledge that is gathered and shared as part of the clinical ethics consultation process.

Epistemic justice refers to the patient's right to be treated with fairness and be recognized as an epistemic subject in possession of knowledge. It includes the patient's right to be heard in decisions that affect them and/or their care.

While PP in CEI does not guarantee procedural or epistemic justice, it reduces the risk of injustice.

Four cases:

¹ Eijkholt, M. Patient Participation in Clinical Ethics Interventions: A Requirement of Procedural and Epistemic Justice. *Bioethics*, 2026; 40:159-167.

- Scenario one describes a situation where the patient was unconscious and didn't have a substitute decision-maker (SDM). In this scenario, the team was inclined to continue life-sustaining treatment, believing that the patient's previously expressed wish to stop treatment was delusional. However, the team decided to seek out information from the patient's friend who was able to provide insight into the patient's wishes and values, and it was decided to withdraw life-sustaining treatment. Thus, risks of procedural and epistemic justice were mitigated by seeking input from the patient's 'social family.'
- In scenario two, a patient requested CEI as they didn't feel heard by the medical team. The patient wanted to be discharged, but the health care team disagreed because of the risks to safety for the patient. The CEI process revealed differences in values and dignity of risk between the patient and the healthcare team members. Had the patient not reached out for ethics support, his perspective would not have been heard.
- Scenario three outlines a CEI where a medical team were to decide whether to offer potentially life-sustaining treatment for a severely ill baby. The decision not to offer further medical intervention was made entirely by the medical team without consulting the parents. The author argues that irrespective of the outcome, the lack of PP in this situation challenges both procedural and epistemic justice.
- Scenario 4 is a variation of scenario 3. In this scenario the medical team wanted to place a feeding tube believing that the child wasn't suffering, but the parents objected. A CEI was requested, and the parents were included. The consultation revealed important information about the child's level of comfort and suffering while in hospital versus in their home environment. Without PP in this case, the understanding of the child's level of suffering outside the hospital setting would likely not have surfaced, and thus, pp enabled decision-making based on a more complete picture of the child's condition.

The four cases demonstrate how PP can mitigate procedural and epistemic injustice in CEI. It allows space for the patient's voice to be heard, and can bring important knowledge to the table, that may otherwise be overlooked by the medical team. The cases illustrate that while ethics consultation is generally advisory, they may also be decisive, and their impact on patients can be significant. Excluding patients in ethical deliberation around their care creates injustice, procedurally and epistemically.

Conclusion

Engaging patients in CEIs can promote procedural and epistemic justice. While PP may not have to be part of all CEI, it is important to ensure that policies and standards do not disable the option of including patients in clinical ethics consultation related to their care.