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

Marleen Eijkholt

Department of Medical Ethics and Health Law, Leiden University Medical Centre, Leiden, the Netherlands

Correspondence: Marleen Eijkholt (marleen.neuroethics@gmail.com)

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ABSTRACT

The question whether or not patients ought to be involved in clinical ethics interventions (CEI) remains unresolved. While generally it has been recognized that patients' active participation in health care decisions and processes is important, this is not unequivocally accepted for CEIs. Patient participation in CEI (PP) is common in the United States, but PP seems far from the prevailing practice in Europe. In Europe, CEIs often involve discussions of the ethics issue by the healthcare team only; the patient or proxy is not included, consulted or even informed about such an intervention. In this paper, we submit that policies or standards which resist PP and disable it as an option conflict with procedural and epistemic justice requirements in CEIs. We conceptually develop how the two concepts of procedural justice (PJ) and epistemic justice (EJ) relate to CEIs and to PP. We also engage with four cases to illustrate the risks of injustices and how PP facilitates CEIs to meet justice requirements. We conclude that in settings where CEIs systematically do not involve PP, and where patients are neither asked about the ethics issue nor informed about the intervention, policy and practice presumptions should be adjusted.

1 | Introduction

While generally it has been recognized that patients' active participation in health care decisions and processes is important, this is not unequivocally accepted for clinical ethics interventions (CEIs) [1–4]. Patients are included in informational and decision-making processes in healthcare, in many different forms and under a shared decision-making umbrella,[1] but such cannot be said for discussions on complex ethics matters in CEI [8].[2] In fact, patient participation in CEI (hereafter: PP) is a matter of debate and contention in the global context. PP, which is defined in this paper as an occasion in which a patient is directly consulted on an ethics issue in their care,[3] is a widespread occurrence in the United States [9, 10]. CEIs are considered part of the shared decision-making process in the United States [11], so PP seems obvious. Yet, PP is not a common practice in many other parts of the world. It seems rare in Europe and Oceania [1, 12]. The literature about these settings describes few occasions of patients being included in CEIs or them even being informed about such meetings. In these regions, the practice of CEI does not seem part and parcel of the shared decision-making process overall [13].[4] PP happens in Paris, but PP does not seem to happen in the rest of France [2, 14]. In Norway, there is some experience with patient involvement [15, 16]. In the United Kingdom, patients are involved in CEIs in some places and on some occasions [2, 17]. In the Netherlands, PP seems an exception [1]. Despite these exceptions, objections and resistance to PP outside the United States is still predominant in practice and in the literature [14]; in many countries, PP seems the exception rather than the rule.

We submit here that policy or standards which resist PP and disable it as an option conflict with procedural and epistemic justice requirements in CEIs. PP should be a possibility when the topic matter is fitting for PP and the CEI pertains directly to the patient's care. Where CEI practices systematically disable

the option of PP and patients are not actively engaged in the CEI process or informed about the ethics issue at stake, these standards should be adjusted.

Introducing our claim below, we start by specifying the realm of relevant CEIs in which PP should be a possibility. Then we submit how the two concepts of procedural justice (PJ) and epistemic justice (EJ) relate to CEIs and, in turn, how PP serves as an instrument for justice. Subsequently, we engage with four typical CEI scenarios. These illustrate how PP relates to issues of procedural and epistemic (in)justice. The scenarios involve a whole spectrum of issues and set ups of CEIs; they even include a case where the patient called the CEI service himself. Then, we delve into the PJ and EJ requirements in more detail and show how, also in light of shared decision-making practices, CEIs require the option of PP. While some participatory practices have been defended by references to 'good practice' and transformative reasons [4, 18], and could be supported by further substantive and relational arguments, our proposal seeks to make a novel argument drawing on deontic, consequential and instrumental arguments and foundations in epistemic and procedural justice.

2 | Clinical Ethics Interventions and Patient Participation

The argument for PP as a matter of justice in CEI might be received as superfluous in the USA. Studies suggest patients to be engaged in 73%–96% of cases [9]. PP features even explicitly in American standards on ethics consultations [10]. These state that ethics services should 'inform the patients when an ethics consultation has been requested ... and seek patients' agreement to participate' [10]. PP is part and parcel of common standards and practices. Both CEI and PP seem recognized as pieces of the shared decision-making process. The historical roots of CEI in the civil rights movement might have something to do with this [19, 20]. In the United States (clinical) ethicists are 'to ensure a fair and inclusive shared decision-making process' [21].

In contrast, PP seems far from a common practice in Europe and Oceania [1, 12]. Statistics are missing, and there are no standards formulated on the matter. While CEIs may vary in set-up, the literature describes that CEIs involve mostly meetings of healthcare professionals who are joined by an ethics consultant or a facilitator. Together, they discuss the ethics issues central to a specific case. Typically, patients or proxies are not included in these CEI meetings, nor do they seem to participate in any other form in these interventions or are they even informed about them [1]. The literature and empirical studies reveal somewhat of an increasing support for PP [4, 8, 22]. Concerns about harm for patients, for example, have been addressed and rebutted by Norwegian empirical studies; these revealed that patients and next of kin want to participate. They valued attending and participating in meetings more than that they experienced 'too heavy a burden' [16]. Still, objections and resistance against PP are dominant in the literature and in practice [1, 14]. While patient participation might be a widely established practice in healthcare overall, including in Europe and Oceania, and might even be perceived as a general moral imperative [23], this is not the case for CEIs. Hence, our call that policy and practice need to incorporate the option of PP.

In our call to enable PP, we do not argue that it should be an option in all CEIs. CEIs can be about many different issues, and not all CEIs lend themselves for PP.[5] Nor do we argue that PP is an absolutely necessary requirement for CEIs. We agree with the USA standards that demand respect for a patient's or proxy's refusal to be involved [10]. Yet, PP should not be systematically disabled and should be possible where CEIs meet at least four criteria. PP should be possible where CEIs involve (1) an ethics issue related to patient care, and (2) this issue relates to a current and ongoing case, (3) a person from outside the immediate health care team, such as an ethics consultant, is requested to come in and to discuss this ethics issue in a current and ongoing case, and (4) this person is to be involved in these discussions under an 'ethics hat'.[6] Once interventions fulfil these four criteria and the topic is suitable,[7] PP should be an option. PP would make the CEI based in a more complete picture and therefore more egalitarian and just.

3 | Clinical Ethics Interventions and Procedural- and Epistemic Justice

Before outlining the definitions of procedural justice (PJ) and epistemic justice (EJ), and discussing how PP is an instrument to promote both justice requirements, we provide a general argument that CEIs need to meet standards of justice. Without rehearsing some strong arguments from the literature that procedural justice applies to CEIs [24], we submit that the requirements of justice in CEI are broader than argued before and include epistemic and further participatory components. Many elements, topics, and processes in CEIs are typically concerned with questions about patient rights and entitlements. The issues central to CEIs often boil down to questions about who gets what and to questions regarding the distribution of scarce services [24]. CEIs regularly regard decision-making processes and the division of scarce goods. They regard the organization of health care; they involve social relationships and power structures [24, p. 103,25], and they therefore demand equitableness and fairness. They involve decisions and meetings about high-stakes matters. Hence, CEIs need to meet requirements of justice, whereby PP enables both procedural and epistemic justice.

Procedural justice (PJ) regards fairness in procedures and hearings. It is an umbrella concept that stands for procedural rights and includes due process requirements. PJ comprises a right to hear, gather, and contribute knowledge in a procedure. It contains six elements for a 'fair process', including (1) consistency; (2) bias suppression; (3) accuracy of information; (4) correctability; (5) representativeness: and (6) ethicality [26].

PJ in CEI means that patients would have a right to be informed about the CEI and to be actively engaged with it. PJ requires PP, or at least the option of PP. PJ includes a right to be heard and contribute, *audi et alteram partem*,[8] extending to opportunities to correct misunderstandings or misjudgments that may exist in the care setting. It also includes a right to be present, regardless

of active contributions. PJ serves as a tool to promote 'moral legitimacy for outcomes' in cases without 'consensus on substantive principles of ethical import' [12, 28].

Epistemic justice (EJ), in turn, is about fairness as to whose knowledge counts and whose testimony should be taken into account. It is about recognizing that someone with particular 'knowledge'—the epistemic subject—can offer important contributions and is part of the knowledge exchange. This can be both by virtue of being an epistemic agent, but also through having situational knowledge. EJ is often defined through conceptions of epistemic injustice, which stands for the idea that 'someone can be unfairly discriminated against in *[their]* capacity as a knower based on prejudices about the speaker, such as around gender, social background, ethnicity, race, sexuality, tone of voice, accent, and so on' [29, 30]. In a CEI, the status of being a patient and not being part of the community of medical professionals could easily lead to prejudices and exclusion of their knowledge.

EJ comprises hermeneutical and testimonial components. Both of these are relevant for CEIs and therefore require PP. Testimonial justice is at stake when someone is deprived of his or her credibility, for example, due to unfair identity prejudices or when biases result in the exclusion of evidence [31]. Hermeneutic justice is at stake when there is an inability to articulate experiences or communicate them to others. An example could be the translation of the illness and care experience into medical jargon. An injustice could happen if an interpretative source is lacking for the patient to do this translation. This might occur when available resources are too impoverished to translate or understand patient experiences, from biases due to conceptual limitations in the framework of a discussion [31, p. 184], or from exclusion, when a patient would not be able to access CEI. The exclusion of patients, as relevant stakeholders, has hermeneutical and testimonial consequences. Their exclusion can result in injustices.

Where CEIs concern patient care, they need to meet standards of procedural and epistemic justice. Patient inclusion in CEIs is a matter of patients' right to be treated with respect, a right to be involved in relevant decisions, to be recognized as bearers of knowledge and as entities of equal concern [32]. PP is a function of epistemic and procedural justice in CEI and draws on deontic, instrumental and consequential arguments. And while the option of PP cannot guarantee PJ or EJ, it can mitigate risks of procedural- and epistemic injustices. The scenarios below will illustrate this.

4 | Four Scenarios: Discussions of Ethics Issues With or Without PP

The following four scenarios serve three crucial purposes, namely to: (1) outline some CEI practices,[9] (2) show how procedural and epistemic issues are relevant for CEC, and (3) illustrate the risk of epistemic or procedural injustices in the absence of adequate PP. The cases highlight, for example, how, respectively, the issues of accuracy, correctability and representativeness might arise in CEIs and how PP mitigates these risks for procedural justice. Further, the scenarios reveal how biases around patients and concepts might mean that patient input can create a more complete picture and mitigates these risks for EJ. The first two scenarios are situated in a context where PP is common; they depict how the practice of PP mitigates risks of procedural and epistemic injustice in CEI. The last two scenarios are based in systems where PP is not common; they illuminate how risks for PJ and EJ arise in systems without PP.

4.1 | Scenario 1—the Family Concept[10]

This first scenario involves Ms T. Ms T was a 51-year-old female who was admitted for Type A acute aortic dissection. She underwent emergent AVR/root placement and suffered complications. The CEI concerned inter-team conflict about the surgical team's decision to continue interventions when the patient did not recover and remained unconscious some days after surgery. Not all medical teams agreed that continuation was reasonable and in line with her wishes. She had a grim prognosis, and had expressed preferences about stopping in-between interventions and about consulting her brother. But the surgeons deemed continuation reasonable and in line with the patient's original wishes about the treatment trajectory. They considered the patient's comments about stopping treatment as 'delusional', including the comment about consulting her brother. According to the surgeon, the patient had said that there was no family during intake. Further information about the patient's stance seemed important for deciding how to move forward. However, as stated above, the patient was unconscious at the time of the consult.

To get more insight into the patient's wishes and to decide whether or not to continue treatment, further input seemed indicated via PP by proxy. However, the surgeon stated that there was no one to ask; the patient had said: no family or brother - thus there was no good proxy.[11] Under the prerogative of a first CEI, the suggestion came that family could also be interpreted beyond immediate blood relatives and to include the 'social family'. The social worker located a close friend who had emigrated recently to a faraway country. This person described an extensive social history with the patient and Ms T calling him a 'brother'. This 'social brother' talked about detailed conversations with Ms T's, regarding her wishes and preferences concerning rehabilitation post-operatively and her persistent desires to live independently. Regardless of the legal status of the social brother's testimony, it became clear that further interventions were undesirable under an ethical perspective. Eventually, both medical teams agreed that the patient's upcoming trajectory did not align with the insights about Ms T's preferences, as conveyed by her 'brother'. Ms T was given comfort care and died.

This scenario illustrates how risks of procedural and epistemic justice were present but were mitigated by PP. PP by proxy enabled, for example, correctability elucidating the patient's specific preferences on rehabilitation. Without the friend's input, it is likely that these preferences would have been implied or derived from assumptions about the standard

patient. Important knowledge and testimony would not have come to the fore had the providers addressed the ethics issue without proxy input. Any treatment decision and justification would have been less complete. PP by proxy alleviated risks of inaccuracy about the patient's preferences, at least to some extent. PP made the decisions more procedurally and epistemically just.

An epistemic injustice was at risk of occurring without PP by proxy because of a preoccupation with 'biological family relationships' as the only relevant contributors. The testimony of a friend with extremely relevant knowledge was almost ignored, because of a bias around the notion of family. A preoccupation with biological family members nearly omitted information from a relevant epistemic subject who could testify about the patient's wishes; the friend's testimony had been at risk of exclusion under the narrow conception of family and who could know about the patient's wishes. Recognition of the friend as a relevant 'knower' and as a relevant proxy, contributed essential information; his closeness as a 'brother' justified the legitimacy of his input.

4.2 | Scenario 2—An Assertive Patient[12]

This scenario involved Mr S, who was a 39-year-old male admitted for severe muscle spasms, edema and pain. Mr S complained that he was held in the hospital against his will on unjust grounds of 'safety concerns'. Familiar with the hospital system, the patient had called the ethics service himself. Mr S argued that the state of his illness and his concerns about his hospitalized status had been dismissed by providers under a narrative of risks about safety. The patient did not perceive the same risks as the providers. The CEI concerned the difference in views on risks between the patient and providers, and the question about what should happen with the patient's wish for discharge. This included concerns about capacity that were hidden from the patient but were conveyed by the providers.

Risks of procedural and epistemic injustice were clear from the outset. Providers did not agree with the patient's testimony and dismissed the idea that an ethics issue existed in their decision to keep the patient in the hospital. They did not see his concern as a matter of ethics, but as a medical assessment; they told the ethics consultant that this patient's addiction history meant that he could not be safely discharged, irrespective of his desires. Providers described the patient in their narratives as a drug seeker and a 'borderliner'. This label and implicit biases about the patient's state of illness and capacity seemed to have driven some perceptions about the patient's testimony and the dismissal of his views about risks.

The scenario illustrates how PP mitigated some risks of PJ and EJ. Mr S' individual access to the CEI, as well as his testimony, led to some procedural correction in terms of representativeness. Regardless of the ultimate outcome, his participation meant a recognition of the situation, of his concerns and values at stake, of Mr S as an epistemic subject, alongside establishing the providers' decision as a matter of ethical concern. The process revealed a difference in values around safety and freedom and in what, arguably, a decision which should have been a matter of shared decision-making. Without Mr S's access to the ethics service, the patient's complaint 'would have been muted.' Accordingly, PP and the access to a CEI created a forum for the patient's knowledge. PP contributed to PJ and to epistemic endorsement; the patient's issues and perspectives were now heard.

Epistemic justice issues were at stake as the providers' decisions and judgments seemed influenced by biases about the patient. It seemed that their perceptions of the patient drove views on the issues and the patient's right to be heard and present evidence. Yet, the patient's testimony became part of the process through his appeal for help from the CEI; PP served both procedural and epistemic justice. Regardless of the outcome of the CEI, Mr S's involvement was important and enabled through PP. Access to and testimony in the CEI mitigated risks of hermeneutic injustice and offered a platform for sharing knowledge.

4.3 | Scenario 3—Providers and Perspectives on Suffering[13]

Scenario 3 involved baby Z, who was born with a congenital muscular illness suffering severe epileptic fits. A CEI was called about various questions, including whether or not to offer a feeding tube, and whether or not to continue interventions for Z and offer a hemispherectomy. The CEI involved discussions between health care providers, including the ethics consultant. Central to the discussion was a piece of paper that laid out components of 'suffering'. After some back and forth, the providers decided that Z's suffering would be too great and that no interventions would be offered. Interventions were deemed disproportionate, futile and not medically indicated of for the child's best interest.

Z's parents were not included in the discussions about the suffering and the interventions' proportionality. This absence of PP challenged procedural and epistemic justice requirements; exclusion of the parents meant that they were not allowed to contribute perspectives on whether or not a short life span could be worthwhile. The provider-only discussions originally sought to answer the question whether or not the interventions would be indicated. Yet, the ultimate decision relied mostly on provider-value-based ideas about proportionality and suffering. The other perspectives were not heard.

PP would have made the decision more epistemically and procedurally just, regardless of the outcome. The decision was based on provider-only perspectives on suffering and harm. Since the ultimate decision concerned the child's best interests, medical expertise was not the sole relevant perspective. Views on interests and harm need multiple stakeholder perspectives [34]. Moreover, important testimonial facts and statements are likely not to have come to the fore; there was no equality of parties. The absence of PP challenged both procedural and epistemic justice.

4.4 | Scenario 4—Providers and Perspectives on Suffering-2

Scenario 4 is a variation of scenario 3, where the providers did not perceive the child to be suffering; they did not see this.

In this variation, the child did not have epileptic seizures, but her premature death was inevitable due to her condition. She would likely live another 1–3 years. One of Z's parents objected to the feeding tube placement, given Z's state and future quality of life. The other parent, who was initially uncertain, also resisted the idea that placing the feeding tube was the right thing to do. However, the main providers at the time of the consult were uncomfortable letting the child go. They believed the tube would have to be placed; the child was not suffering and seemed comfortable under their care. Hence, they called a CEI to discuss the placement of the feeding tube and to form a unilateral treatment plan; the CEI would have been by providers only.

PP, which happened in this case by accident, highlighted how procedural and epistemic justice issues arose out of provider-only discussions. Obviously, the accidental nature of the parental involvement could be considered a procedural justice issue on deontic grounds. But even beyond that, instrumental arguments are also at stake. A CEI had been planned with providers only. Coincidentally and against usual practice, the parents joined in and talked about the situation at home, where the child was never comfortable.[14] They offered unique testimony and knowledge in the discussion of the ethics issue. Information about the uncomfortable state and suffering of baby Z in the home setting would not have emerged otherwise. Without PP the decision would have been based on perceptions about the patient's comfort level in the hospital. Providers had not reflected on the 24 h/home environment, and assumptions about the patient's comfort level had not been corrected.

Aside from the deontic argument for PP, it is hard to contest the instrumental value of PP in this CEI. Knowledge about the child's level of discomfort in the home setting would not likely have surfaced without parental input on this particular issue. Had the physicians' discussed the ethics issue among themselves, the process and the outcome would have been ethically inferior. Had providers decided to place a feeding tube, this would have been based on an incomplete picture of the situation and, arguably, on a bias about the child's state of being and health. If the child was to live its life mostly at home, the child would have suffered according to the parents. PP offered the providers a possibility to appreciate the parents' perspective carefully under the angle of an ethics consult. Eventually, the parental testimony as PP, led to the decision to forego placing the feeding tube.

5 | PP to Mitigate Procedural and Epistemic Injustice

As illustrated in the scenarios, PP mitigates risks of procedural and epistemic injustice in CEI. PP facilitates the testimonies and input from the different parties in the CEI. It generates more even-mindedness of different relevant views. PP can boost the promotion of well-balanced knowledge and testimonies. It reinforces patient-centeredness by acknowledging patients as part of the conversation. Accordingly, PP fits with the requirements of justice and the promotion of just health care [35]. Like in matters of shared decision-making, PP in CEI alleviates the potential for epistemic and procedural harms that might come from a one-sided provider-only narrative.

The scenarios above highlighted the risk to PJ without patient participation. PJ, as described, requires fairness of process. This is relevant for dispute resolution processes and resource allocation procedures [36], which are exactly the issues in our cases. PJ requires transparency about how and which decisions are made [37], and clarity on who makes the decisions, also for reasons of trust [38]. PP, in our four cases, enabled transparency about the decisions that were made and the people involved in the process. The scenarios illustrated that PP contributed to patient notification, but especially to more equality in the process. Without PP, the right to present evidence would have been challenged in our cases. Accordingly, PP enabled more PJ aside from facilitating EJ.

Questions have been raised about the applicability of PJ in the CEI context [24, 25]. Critics suggest that CEIs do not offer binding outcomes and fall therefore outside the realm of PJ. In turn, PP would not be needed for reasons of justice. Yet, our scenarios highlight why this criticism needs to be rejected; the scenarios reveal several elements of CEI that illustrate why PJ should be applicable to this context. The scenarios show that CEIs have features resembling court decisions. CEI outcomes might not always be decisive, implemented or even sanctionable, but they could be decisive and they are not just advisory either [8, 25, 39]. CEIs affect patients and persons [40]. CEIs should therefore fulfill PJ requirements. CEIs have significant impact and they are geared to influence clinical behaviour; they pertain to patients and resources, as all our scenarios illustrate. CEIs engage health care providers with administrative power and control. This requires concern for PJ. PJ is applicable as a substantiation of a patient's right for respect and equal concern [40, p. 26]. PJ fulfils dignitarian and participatory values in CEI [41]. So, even if CEI processes are not presided over by a judge, or necessarily organized under an official authority, PJ requirements apply to balance out power differentials. As Ballantyne proposes: 'As CESS[CEI] have an impact on patient care and the allocation of resources, they should be obliged to follow basic principles of due process' [12]. The scenarios above illustrate that CEIs can be foundational for important clinical decisions, which would require PJ. PP could serve participatory legitimation, as required under PJ.

The scenarios above equally highlight the risk of epistemic injustice in CEIs without patient participation. Epistemic injustices occur when 'someone is ingenuously downgraded and/or disadvantaged in respect of their status as an epistemic subject' [30]. Exclusion of patients in CEI has testimonial and or hermeneutical consequences. Patients have a unique type of knowledge to contribute. To exclude patients, as a relevant stakeholder, results in an injustice.

The scenarios highlight how PP could be an instrument towards EJ. Scenario 2, for example, revealed negative identity preconceptions and biases which prevented the patient from being heard [42, 43]. The scenario also depicts how PP enabled validation of the issue and an actual process; both through

access to and participation in the CEI. The scenario highlighted how PP facilitates EJ. PP mitigated risks of hermeneutical injustice. Access to the CEI created a forum to advance views and values. As shown by the scenario, PP allows the ability to detect if the patient and the provider agree on the understanding of the situation. It enables assessment of questions such as if the healthcare professional is accurately reporting the patient's voice and perceptions, or whether they are perhaps minimizing them; if parties agree on the ethics issue at stake, as illustrated by all the cases. Without access to or from the patient it is otherwise impossible to know if the input and decisions in CEI are based on a full and accurate picture of the situation. Moreover, the CEI and PP involves an outsider—the ethics consultant—and enables third parties thereby to uncover if any hermeneutic or testimonial injustice is incurring, facilitating accountability and accuracy. Scenario 4 illustrated how testimony about the child's experience at home complements the providers' viewpoints and made the decision more complete. The parent's testimony offered hermeneutic equivalence.

PP might not necessarily solve all PJ and EJ concerns, but it would be an improvement from provider-only discussions. For example, while PP is unlikely to eliminate all bias, it provides more opportunities to fulfill PJ requirements. It promotes that more information and more perspectives are heard, so that biases can be reduced more easily and procedural justice can be better served. This accounts for EJ as well. Scenario 2 illustrated how providers alone are unlikely to mitigate epistemic justice risks themselves: providers are likely to have stereotyped the patient, and are known to do so in other cases [44, 45].

6 | PP as a Matter of Shared Decision-Making and Requirement of Justice

In regions where participation of patients is systematically disabled in CEI, CEIs do not seem part of the shared decision-making process (SDM). After the reflections on EJ and PJ, this is hard to understand. SDM and PP fit with ideas that patients should be a full partner in moral dialogue that concerns their care and in which they are a stakeholder, if they so desire [46]. PP, like other SDM experiences, enables patients to express, for example, their illness and care experience [47, 48]. Such could be extremely relevant in CEI, as the experiences, testimonies and decisions at stake in CEI are nearly always intertwined with matters of value. Although providers might deem some of the CEI discussions merely matters of medical expertise, the involvement of the person under the ethics hat in the CEI, demonstrates that the alleged 'medical matters' harbour controversy and values. Scenario 2 above offered an example where even views on risks and safety were explicitly value-laden and guided decision-making.

PP, like SDM, is furthermore crucial to counteract settings with specific power dynamics that 'predominantly privilege the knowledge of clinicians, policymakers, and researchers' [48]. As SDM is a matter of recognizing respect for the patient, their values and their self-determination, PP is a matter of respect for self-determination through offering a chance to notice and participate in the process. Both the illness and care experience can be sources of value and sources of conflicts, as illustrated explicitly in scenario 2 and 4. To exclude patients, and to exclude their knowledge or testimonies in conveying their perspective on the decisions and the ethics issue and to separate it from the SDM, creates an injustice. In regular medical decision-making and information exchange, the process is based on transparency and trust under SDM [49, 50]. Since CEIs are the main locus for ethical deliberation in patient care, there is no good reason to deem that such values would be different for sharing of information in CEIs [46], especially where these involve decisions about patient care. Making the patient an 'integral part of the process' is a deontic requirement and also facilitates the values of trust and transparency [51]. Keeping the patient out of the deliberations challenges such values.

PP is foundational for a more complete overview and knowledge-base. PP, like SDM, creates the opportunity to establish a richer picture for the decisions to be made, and thus for more procedural and epistemic justice. It should follow the SDM steps. Involving a patient perspective could enrich insights and enlighten providers that there is a value conflict or ethics issue at stake. Involving the primary source of information is crucial for deontic, instrumental, inclusive, and dignitarian reasons. Representation of the patient perspective through health care providers, as might occur in some provider-only settings will not be adequate. Such representation merely creates the appearance of inclusion [52], rather than a true epistemic contribution or epistemic justice. In turn, physicians have often been said to miss a broad understanding of ethical issues and the framework. They may sometimes lack ethical sensitivity or fail to identify a difficult issue as an ethical issue [24, 53]. This makes patient perspectives even more relevant.

Engagement with patients in CEI is thus a necessary constituent for transparency and in the democratization of health care. Patients are epistemic subjects who have generated and provided knowledge. CEIs can pertain to the SDM context. As long as the patient has been given an opportunity to participate in relevant cases, we consider this compatible with justice requirements. Systematically denying patient access to the CEI or even denying information about PP taking place, however, means denying access to a relevant stakeholder with important knowledge and goals. It would leave a piece out of the SDM-puzzle. PP enables patients to access and accede to a decision-making body, which otherwise would be constituted of healthcare-providers-only (Box 1).

7 | Conclusion

CEI can happen without PP. We see such practices in Europe and Oceania. We argued, however, that practices which systemically disable the option of PP fails to accord with procedural and epistemic justice requirements. Standard practices and policy assumptions that hinder PP should therefore be adjusted. PP, or at least the option of PP in relevant cases, is crucial for deontic, instrumental and consequential reasons and makes CEI settings more legitimate and fair (Box 2).

BOX 1. | Case 1—The Family Concept

Upon admission, the cardio-thoracic surgeon asks if Ms T has any family to consult, but Ms T says she does not have family. She wishes to undergo this complicated procedure and accepts the risks. Ms T subsequently suffers several cardiac arrests on the floor. Between her cardiac arrests, she states that she wants to die. But per the psychiatry assessment at the time, she does not have decision-making capacity. After her second arrest, the intensive care team suggests that her clinical picture does not look promising. The thoracic surgeon, however, suggests that Ms T still has a fair chance for recovery to a good quality of life as per her baseline. Her MRI does not explain a poor prognosis. Her prior medical history is quite extensive. According to the thoracic surgeon, her quality of life was already diminished upon entry into the hospital, and recovery to baseline is possible. The ICU team does not agree with the surgeon and points to a statement in her chart. This statement reads: No resuscitation desired in case of a poor prognosis, and that upon an arrest, the doctors are supposed to call her brother. The cardiothoracic surgeon states that the patient indicated not having any family in their conversations.

BOX 2. | Case 2—An Assertive Patient

Mr S' prior medical history is extensive. He recently changed providers, with whom he had agreed to try to use off-label therapy. In the hospital setting, the narrative around his care involves Mr S abusing drugs at home and in the clinical setting too. The patient is also said to have a borderline personality disorder, that has never been officially diagnosed. While Mr S wishes to go home with a peripherally inserted central catheter (PICC) line so that he could self-administer the treatment at home, the providers do not want to let him go. They see him as drug-seeking and feel discharge with PICC line is unsafe. Such line would entail the risk for abuse in the home setting as well as entail infection risks.

Our submission does not answer all questions around PP. For example, we could ask which potential modes of PP would be most appropriate for CEIs, or how different settings might require different approaches to PP. Research could also address questions who should execute and ensure PP, and if PP in CEIs can be adequately performed in full ethics committee constitution or if it requires consultants to engage with the patient separately to avoid a tribunal perception. As CEI practices require adapting and are evolving [54, 55], these are important questions to address to optimize PP, especially in Europe and Oceania. Yet, despite the need for further research into the most optimal shape of CEI and adequate types of PP, these observations do not take away from the stance that PP is an indispensable tool in CEI. PP enables patients to be part of discussions about the ethics issue at stake. This is accordance with procedural justice and recognizes their testimonies as an element of epistemic justice in CEI (Box 3).

BOX 3. | Case 3—Providers and Perspectives on Suffering

Baby Z's type of congenital muscular disorder was rare, and the child's prognosis was therefore uncertain. Z would likely have difficulties communicating, acquiring words, and would be dependent on assistance for all tasks of daily life. Z was unlikely able to walk independently. Z's condition and epilepsy required a feeding tube, and anti-seizure medications. A hemispherectomy would improve Z's condition to some extent, although the actual benefits of the procedure were uncertain. Epileptic seizures would increase at some stage, and there was no more chance for improved quality of life. Other children with this condition had reached a maximum vocabulary of 80 words. Life expectancy of other children had been really dependent on the patient's supporting system, but had reached up to 40 years life-span. Z did not have any life-threatening conditions.

The providers' discussion about suffering involved a list with checkmarks including epileptic seizures, ability to talk, walk. The team initially disagreed about what to do. Some providers suggested that a short life span could still be worthwhile even with a limited vocabulary and with some epileptic seizures. However, after some discussion the providers decided not to offer the operation and to suggest that continuing interventions would not be medically indicated; Z's suffering would be too great.

The provider-only discussions meant that the parents were not included in value-based discussions; they were not given any options or choices. The options, or lack thereof, were based on provider-values.

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Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analysed in this study.

Endnotes

[1] See Thompson [5], Vahdat et al. [6]. And for a more general typology of participation the participation ladder of Arnstein [7].

[2] Many complex questions exist about the degree or type of patient participation in CEI, or the exact occasion suitable for PP. These complex questions will be addressed in another paper and study. The premise in this paper is not even the minimum criterion of participation—being informed about—is met in many geographical locations. See for different specifications of participation, for example, Brierley et al. [8].

[3] In case the patient is unconscious, consultation would extend to the proxy decision-maker.

[4] Clinical ethics interventions are not a uniform concept. Some interventions constitute individual consultants, teams of consultants, ethics committees or general providers with some ethics practitioner. While the discussion in the USA is still there, concerning individual

versus team consultation, the more broad discussion on the method was certainly a matter of debate in the past.

[5]While many CEIs will relate to a question about patient care, some might not concern patient care nor relate to a question or issue that would be suitable for patient input. For example, CEIs might be organized for policy formation or for educational purposes; the care relation is not pivotal to the consult. Cases on legal questions or on inter-team conflicts do not require PP either; patient views are not central to the conflict, and the patient's knowledge or testimony is not crucial to these cases. Such CEIs are not included in our plea for PP.

[6]Criteria 3 and 4 are typical elements of a CEI, making the discussion of the ethics matter an 'intervention'. The person from outside the immediate health care team, who will be involved under an ethics hat, may be a person professionally licensed as a clinical ethicist, such as a HEC-C in the United States, but could also be providers from a different health care team of someone from spiritual care, for example, who are designated to come in for the 'ethics question'; worldwide there are different systems and levels of formality of ethics engagement. What would make such intervention specific, however, is the request to focus on the ethical angle in the issue, rather to focus on the spiritual or medical question that may play a role. Whereas these interventions are typically referred to as clinical ethics consultations in the USA and to moral case deliberation sessions in various European countries, we use the term clinical ethics intervention here, to encompass all these phenomena.

[7]It is not within the scope of this paper to fully engage with a discussion about what should be considered a CEI or not. Suffice it to say that we deem these four criteria indicatory that values and preferences are likely at stake and that perspectives, knowledge and understanding from outside the immediate health care team are necessary to resolve the issue.

[8]The term 'natural justice' has also been used in this context [27].

[9]The practice of PP can be related to the practice of shared decision-making. Some CEIs might indeed reveal the absence of shared decision-making or inadequacy thereof, and facilitate in this process. See also the penultimate paragraph of this paper. But CEIs could also go beyond these issues. See also López-Urrutia et al. [33].

[10]Please see textbox 1 for further information about the case.

[11]Proxy can be a legal term and be understood by a predefined range of people, such as a spouse. It can also have a broader meaning that refers to a substitute decision-maker who knows the patient best.

[12]Please see textbox 2 for further information about the case.

[13]Please see textbox 3 for further information about the case.

[14]Providers recounted feeling cornered through PP, afterwards, and unable to contradict the parents. However, we pass over the question about the relevance of the providers' feelings of ethical discomfort. We will not address either how they should be valued compared to the parents' ethical discomfort. Instead, our focus here on whether PP supported procedural and epistemic justice.

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