

## Disputing with Patients in Person-Centered Care: Ethical Aspects in Standard Care, Pediatrics, Psychiatry, and Public Health

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### Abstract

This article explores ethical aspects of using open argumentation in person-centered care (PCC), where health professionals (HPs) openly criticize or contradict factual claims, assumptions, preferences, or value commitments of patients. We argue that such *disputing* may be claimed to have an important place in advanced versions of PCC, but that it actualizes important clinical ethical aspects of doing such disputation well. This may prompt caution in the implementation of PCC, but also inspire educational and organizational reform. We also probe the notion of openly disputing with patients when PCC is applied in less standard settings (where it is nevertheless advocated), using the cases of children, psychiatry, and public health interventions, such as antibiotic stewardship programs, as examples. These contexts offer new reasons for why PCC may or should include open disputing with patients, but also introduce new ethical complications. Some of these may transform either to arguments against PCC implementation in these areas, or to a more open view of the extent a HP may seek to dominate patients in a PCC setting. We are especially skeptical of the meaningfulness of applying advanced PCC in areas of psychiatry with high levels of compulsory elements, such as forensic psychiatric detention.

Keywords: antibiotic resistance, forensic psychiatry, patient-professional relationship, shared decision-making, vaccination

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## ***1. Introduction***

This article explores ethical aspects of using open argumentation in interactions between health professionals (HPs) and patients in a person-centered care (PCC) context. We recognize this area as an important aspect of bedside clinical ethics when the care process involves extended communicative interaction between a HP and a patient. More specifically, we analyze the idea of HPs openly criticizing or contradicting factual claims, assumptions, preferences, or value commitments of patients in the course of such communicative interaction. In the next section, we argue that such *disputing* may be claimed to have an important place in advanced versions of PCC, even to be ethically required, for capable patients in standard healthcare settings. However, *how* to best dispute with patients remains a clinical ethical challenge. We then probe, in section 3, the notion of openly disputing with patients when PCC is applied in less standard settings (where it is nevertheless advocated), using the cases of children, compulsory psychiatry, and public health interventions as examples. These contexts are found both to offer new reasons for why PCC may or should include open disputing with patients, but also to introduce new ethical complications. Some of these may transform either to arguments against PCC implementation in these areas, or to a more open view of the extent a HP may seek to dominate patients in a PCC setting.

## ***2. Open Disputing in Standard PCC***

PCC is usually explained in terms of three ingredients. First, there is the idea of the patient narrative, which involves HPs to actively collect and take into account the patient's own story of the health problem that prompted contact with healthcare, how treatment proceeds, and how all of this relates to the patient's own experiences, life, and views in general. Second, there is the notion of a collaborative process between HPs and patients when defining what the problem is, setting aims for the care, identifying options, and deciding on

management (such as choosing and designing treatments). Third, there is a notion of assuring continuity of this process, documenting and revisiting what has been going on, adding to the narrative, and collaboratively revising former decisions (Ekman et al. 2011; Luxford et al. 2010; Mead and Bower 2000; Munthe et al. 2012). The collaborative ingredient has moreover been explained in terms of 'Shared Decision-making' (SDM) (Sandman and Munthe 2010), while the idea of the importance of the patient narrative and what skills are required to handle them has come to be increasingly recognized in terms of 'Narrative Medicine' (Charon et al. 2017).

The ethics of PCC has been analyzed to some extent and it is generally acknowledged that its main aim is about the empowerment and emancipation of patients (Coulter 2002; El-Alti et al. 2017; Entwistle and Watt 2013). It is less clear how these aims are to be balanced against possibly competing considerations, such as HP responsibility and biomedical standards (Gustavsson and Sandman 2015; Munthe et al. 2012), as well as organizational or societal healthcare aims, such as adherence to treatment or efficient use of healthcare resources (Munthe et al. 2012; Sandman et al. 2012, 2016). But even if we grant that health systems and HPs will always set limits to what may be accepted in terms of adaptation to individual preferences of patients, there will in most cases remain a rather wide area of variation with regard to what exact treatments are prescribed, how these are designed and implemented in the individual case, and how the HP in this process balances professional standards with the need to maintain the therapeutic relationship.

Little attention has thus far been given to the more immediate 'bedside' clinical ethics of *how* PCC should be enacted. In standard presentations (Coulter and Oldham 2016; Ekman et al. 2011; Luxford et al. 2010; Mead and Bower 2000), the narrative part of PCC is mostly formulated as urging HPs not to hurry into preconceived biomedical investigations, but to take time and attention to listen and truly comprehend how a health problem is experienced

by the patient, how it plays out in their daily life, and what they value and wish for in relation to that context. Recent works in narrative medicine has called attention to how this requires both humility and interpretative skill, with the notion of each patient as a unique person as a core assumption (Charon et al. 2017). The role of the HP is foremost to facilitate for the patient to tell their story, to follow and respect it, and to achieve a better understanding of the patient's outlook.

This ingredient of PCC may then be fed into a process of SDM, where the HP becomes more active in providing medical information, suggests diagnoses and treatments for the patient to consider and respond to, and so on. The ideal development is often described in terms of a dialogue or a joint deliberation, but this notion can be stretched more or less far (Sandman and Munthe 2010). In the PCC literature, the envisioned SDM mostly resembles the versions that possess what Lars Sandman and Christian Munthe have called "high level dynamics" (Sandman and Munthe 2010: 62). This means that there is room not only for mutual information sharing, but also for mutual critical appraisal of factual information as well as preferences and underlying value stances. In the ideal circumstance, the result will be a consensus, where the HP and the patient manage to create a clinical partnership, and the patient's personal concerns and aims are in harmony with biomedical standards and the professional responsibility of the HP related to these. This process may then rather naturally become a sort of Socratic dialogue, where both parties may dispute some statement or stance of the other, ideally in order to provoke a response and furthering the joint deliberation, ensure understanding, and check for the rationality of presented arguments. Such discussions may be about overarching issues, such as what the overall aims of the care should be: how much it should be based on biomedical standards, how much it should consider personal values of the patient that differ from biomedical ideals (e.g., regarding acceptance of risk). But they may also be about concrete details regarding the design of care, such as fundamental

choices between treatment options (Ekman et al. 2011), or how a particular treatment is discharged in practice, e.g., with regard to dosage of drugs, return visits to the clinic, home- or self-care elements, use of supporting technology, and so on (El-Alti et al. 2017).

This ideal of SDM can be grounded in the underlying value assumptions mentioned earlier: PCC aims to emancipate and empower patients, which in turn is often based on some notion of the value of patient autonomy (Coulter 2002; Coulter and Oldham 2016; Mead and Bower 2000; Munthe et al. 2012; Sandman and Munthe 2009). The HP is supposed to treat the patient with full respect, which includes viewing them as an autonomous person, capable of making their own judgements and decisions. Among other things, this includes accepting that the patient may entertain different factual ideas, value stances, and preferences than the HP does, and that the patient may therefore legitimately contradict or question what the HP describes and suggests. From this perspective, being prepared to openly dispute what the patient says or conveys is a necessary ingredient, as not doing so would seem to mean ignoring the patient's own capacities of judgement and reasoning. Sandman and Munthe (2009, 2010) have described how this means that the joint deliberation of 'high level dynamic' SDM may produce not only consensus and partnership, but also severe disagreement, sometimes prompting strategic compromise. For instance, the HP may be prepared to adjust professional standards and biomedical ideals in order to preserve the therapeutic relationship (El-Alti et al. 2017; Sandman et al. 2012). However, just as much, the HP should be prepared not only to object if a patient seems to reason based on false factual assumptions or does not comprehend the practical implications of medical facts, but also to dispute preferences and value assumptions of the patient that the HP perceives to be in conflict either with central health care ethical considerations, or with what the patient themselves has held out as important tenets of their own. All of this can here be seen as

important ingredients in a HP's struggle to ensure that PCC really actualizes its ultimate aim of emancipating and empowering the patient.

This leaves the question of *how* such open disputing of patient beliefs and opinions should be enacted. Obviously, there is a risk that the kind of open, mutual, critical debate described earlier slides into unnecessary aggression, nastiness, lack of consideration, or manipulative rhetoric.<sup>1</sup> This risk seems more pronounced in view of the fact that professional education for HPs does not focus very much on how to handle 'high level dynamic' SDM (Herlitz et al. 2016; Sandman and Munthe 2010) and this may be a reason for initial caution in fully implementing such extended variants of PCC. However, just as well, it is a reason for considering health professional educational reform in order to pave the way for a broader implementation of PCC that is clinically ethically defensible, or to reorganize clinical decision making so that more room is made for professionals with specific training in handling sensitive discussion and conversation well (such as psychological counsellors).

### ***3. Non-standard PCC: Children, Psychiatry, and Public Health***

The case for PCC and the role of open argumentation within it, especially the reason for why HPs should be prepared to openly dispute patient beliefs and values in the course of SDM, rests on two core assumptions. First, in the standard SDM model, patients are considered fully competent and psychologically 'robust' (Sandman and Munthe 2009). However, in addition, PCC has been advocated for specific areas where this assumption is generally acknowledged not to hold, such as dementia care, in-patient psychiatry, and

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<sup>1</sup> This may also regard the behavior of the patient, and in this way, the notion of PCC and 'high level dynamic' SDM seems to open up an area not merely of clinical ethics, but also the ethics of patienthood. In the present context we will, however, leave this area for future scrutiny and continue to focus on the ethics of HPs.

pediatrics (Herlitz et al. 2016; Munthe et al. 2012). Second, the case of psychiatry introduces areas where patients are subjected to measures based on rationales other than their own personal well-being and where the value of respecting autonomy is often discounted or redefined in more social terms (Joseph 2017; Mezzich et al. 2016), most clearly in the forensic psychiatric setting (Munthe et al. 2010). This introduces reasons that appear to be in conflict with the second assumption of standard SDM models, which is that the aim of SDM should be to promote the interests, or at least autonomy, of the individual patient. Such differing rationales are also present when HPs partake in the implementation of public health programs (Dawson 2011; Munthe 2008), such as vaccination or antibiotic stewardship programs, where PCC has recently been increasingly held out as an important approach (Brown et al. 2014; Fenton et al. 2017; Meharry et al. 2014; Pulcini et al. 2017; Smith et al. 2015; Tindall et al. 2014). In the following sections, we will consider how these differences affect the ethical analysis of openly disputing with patients in PCC.

### *Children and adolescents*

Applying PCC to the care of children and adolescents is both an encouraged and a contested practice (Herlitz et al. 2016; Munthe et al. 2012). On the one hand, person-centered approaches may present an opportunity to empower these patients through promoting their development of more robust decision-making capacities, as well as improving clinical adherence and the health outcome of care (Herlitz et al. 2016). On the other hand, however, the dependency, vulnerability, and fragility of this group has prompted criticism against the notion of applying PCC on a variety of grounds, mostly focusing on how an envisioned SDM may instead lead to *disempowerment*, exploitation, reduced adherence, and harm (Birchley 2014; Delhaney and Galvin 2014; Herlitz et al. 2016). Anders Herlitz and colleagues (2016) have highlighted how a standard SDM process of joint deliberation applied to young patients

with fragile decision capacities may easily become destructive for these patients' long-term development and thereby counterproductive from a health perspective.

A recent analysis shows that the PCC and SDM element of disputing patient beliefs, preferences, and values is especially risky when applied to children and other "fringe decision competent" groups when the patient does not manage the care well, i.e., exactly when the element of disputing the patient's beliefs or priorities may seem most appropriate (Hartvigsson et al. 2018). At the same time, when a patient is doing reasonably well and a safe and trusting relationship is established between them and the HP, minor disputations may very well serve a constructive purpose (Boman et al. 2017). However, these need to be embedded into a strategic design of the SDM aimed at the long-term empowering of the child (rather than momentary promotion of single autonomous decisions) that will limit the room for open disputation from the HP's side (Herlitz et al. 2016).

### *Forensic psychiatric care*

Both of these calls for caution are made in relation to patient features that apply also in the case of psychiatric care (fragile and/or fringe decision competence as well as general vulnerability). However, psychiatry also offers further aspects that deviate from the standard assumptions of PCC and SDM. One of these is that, in psychiatric care, the view of the patient as separated from others as well as society is not as much of a core ethical assumption as it is in somatic care. Psychiatric care makes an allowance for care provision to be dependent, not on the suffering or want experienced by a person with psychopathology, but either on (the potential or actual) suffering of others or on the violation of certain social norms due to the person's untreated affliction. Because of this, not only are various degrees of active restrictions of freedom due to weak decision capacity accepted as a part of psychiatric practice, but also incarceration of the patient in order to prevent harm to others or society. The



most far-reaching aspect of this is probably the detention of severely mentally disordered criminal offenders at forensic psychiatric care facilities.<sup>2</sup>

In this case, the aim of PCC is transformed from promoting the patient's best interest into one about the public good. It may still be possible to speak of emancipation or empowerment as an aim, but these are not necessarily focused on the individual goals and wellbeing of the person, but rather on the conformity to social norms.<sup>3</sup> Because of this, there has been some hesitation in the literature to rush into ideas about PCC in psychiatry for conceptual reasons (Gabrielsson et al. 2015). At the same time, although the aim of individual emancipation and empowerment is certainly the most common ethical aim of mainstream PCC (El-Alti et al. 2017), there is nothing in the concepts of SDM or PCC themselves that rules out versions of PCC aiming for other types of goals (Sandman and Munthe 2010; Munthe et al. 2012).

Nevertheless, the constrained context of a more or less compulsory care setting based on societal aims rather than individual health and autonomy drastically changes the ethical landscape of PCC (Joseph 2017). This also affects the ethics of disputing patient beliefs, preferences, and values in the course of SDM. One preliminary observation that we have made in the course of our ongoing study of forensic psychiatric care is that the common notion of a fundamental, albeit sometimes not yet fully actualized, alliance or partnership between the patient and the HP does not seem to be present as an assumption of the care. Rather, the starting point is a stark conflict of interest: the patients want to live their lives

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<sup>2</sup> An area where some of us are currently undertaking research on initiatives to implement PCC in Swedish forensic psychiatric care.

<sup>3</sup> Sometimes, this ethical transformation is somewhat obscured by terminological shifts, e.g., from a notion of mental health to a concept of 'holistic' mental health, where the individual's wider social functioning is included into the notion of their health (Mezzich et al. 2016).

according to their own ideas, which may then involve harm to others and serious criminal offenses. To be sure, notions about empowering the patient in the sense of having them fulfill the conditions of release from detention are part of the idea of involving them in care decisions. However, at the end of the day, the outcome of this involvement will never be seen as progress unless it means having the patient accepting the prescribed regimen (including medication, movement on the ward, behavior towards fellow patients and staff, compliance to restrictions during temporary leave, et cetera).<sup>4</sup> In other words, SDM here becomes a means of control rather than one of emancipation.

In this context, disputing with the patient openly may, of course, serve a communicative role to the extent that it takes the form of explaining why non-adherence leads to (continued) restrictions. It may also be a part of actual therapy meant to help the patient develop morally through joint discourse on their transgressions (including the offense that lead to them being in this system to start with). At the same time, there is no reason to dispute the patient's wish to be free, or to be given eased restrictions. As there is therefore very little room for compromises or adjustments that would resolve the adversary relationship between HP's and patients, there is an obvious risk that disputing with patients may unnecessarily provoke aggressive conflict on the ward. For this reason, there is no room for a high-level dynamic SDM about how to design the care. SDM-like interaction will instead boil down to explaining to patients that they have to either comply with care instructions and thereby possibly gain emancipation, or refuse to comply and remain in restricted circumstances.

### *Public health*

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<sup>4</sup> These preliminary analyses are presently being further investigated through interviews with forensic psychiatric caring staff. Results are planned to be published in the near future.

There are some parallels between the ethical context of forensic psychiatric care and that of public health in that the latter is also concerned with the pursuit of societal rather than individual aims (Munthe et al. 2010). At the same time, the goals of public health have more immediate links to the value of individual health, as they are in various ways dependent on the latter, and most public measures are not as coercive as forensic psychiatric care.<sup>5</sup> Nevertheless, there are well-known conflicts that may occur between activities aiming to promote public health values and the individual wellbeing or autonomy of a particular patient (Dawson 2011; Munthe 2008). For instance, while vaccination against potentially epidemic diseases may be perceived as beneficial to a person, this person need not view it as such, but it will nevertheless be an important endeavor from a public health standpoint to have many people vaccinated (Verweij and Dawson 2004). In the context of antibiotic resistance, there are good reasons to try to reduce consumption of antibiotics in cases of milder infection in order to mitigate resistance development. Yet, individuals may nevertheless have strong needs and wants to have such drugs prescribed (e.g., due to personal situation, cultural perception, or social pressures) (Littmann and Viens 2015). In that context, the aim of PCC will not primarily be about trying to emancipate and empower patients, but to use SDM to convince them – even manipulate by selecting what information to highlight – to participate in collective campaigns to promote public health aims. In the case of vaccination, less than a joint deliberation, the SDM will be designed in order to construct a rhetoric persuading people to immunize themselves and their children. In the case of antibiotic stewardship, prescription options that might have benefitted or promoted the patient's autonomy and health may be

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<sup>5</sup> Albeit some may very well be, such as in the case of forced isolation and quarantine in serious epidemic situations.

restricted, and patients will also have to be motivated to refrain from accessing antibiotics in other ways (e.g., by seeking a second opinion or by purchasing drugs online).

This process may very well involve disputing patient beliefs, e.g., about the safety of vaccines or of the health benefits of antibiotics, but to what extent it should, depends mainly on whether that would be an effective way of influencing patient behavior in the desired direction.<sup>6</sup> Likewise, initiating a critical dialogue about the personal responsibility of contributing to important collective benefits or public goods, thereby possibly disputing the patient's preferences and moral or political views, may be attempted. However, whether or not it would be an appropriate part of the SDM would again depend on its effectiveness in producing the desired behavior.

The standard context of PCC and that of public health thus pursue quite different ultimate aims. However, it is not obvious that disputing patient beliefs, preferences, and values in the public health PCC context would be necessarily contrary to the aims of patient emancipation and empowerment in the way it appears to be in the forensic psychiatric setting. Trying to convince people of changing their views and minds is not as such an infringement of autonomy or destructive to a person's ability to control their own life. Rather, just as in the standard PCC setting, it can very well be viewed as the ultimate expression of viewing and treating the patient as a person, where the social context highlighted by the public health perspective may activate new beliefs and ethical stances compared to the typical healthcare setting where the patient's individual life and health are the main focus. As in the standard

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<sup>6</sup> Probably also with an eye to the long-term legitimacy of public health authorities and the need to maintain public trust (Selgelid et al. 2006).

case of PCC, this will mainly depend on *how* the disputing is enacted in the clinical encounter.

#### **4. Concluding discussion**

In the standard PCC setting, for the HP to initiate joint critical deliberative SDM and, in that context, be prepared to openly dispute the patient's beliefs, preferences, and underlying ethical or value stances, seems to be well motivated by the typical PCC ethical underpinning of respecting patients as persons, and promoting their empowerment and emancipation in the healthcare context. However, as open argumentation is for many people associated with anger and hostility, it is a matter of some delicacy *how* it is done. The HP needs to be receptive to an equally critical perspective from the patient towards themselves, but also to master the communicative challenge of maintaining an open critical discussion without negative emotional side-effects. As HP education is normally not designed to provide much training in this area, this may be a reason for some caution in introducing far-reaching PCC variants with a 'high level dynamic' SDM. However, insofar as the aims of standard PCC are seen as ethically sound, just as much, it provides a reason for education or organizational reform to fill the indicated competence gap and make way for ethically responsible implementation of advanced PCC clinical practices.

It is unclear to what extent this argument extends throughout healthcare, as many patient groups and situations do not perfectly match the standard PCC assumptions. Such deviation from standard PCC is exemplified by three recently advocated and debated areas of PCC application, namely pediatric care, psychiatry, and public health. Both the pediatric and the psychiatric context highlight the fact that large patient groups may not meet the standard PCC assumption of patients as 'robust decision-makers', but have considerably weaker or more fragile capacities than the model patient typically painted in descriptions of PCC. The

compulsory – especially the forensic – part of psychiatry and public health illustrate that broad segments of healthcare activities do not have the emancipation and empowerment of individual patients as a main objective. We have therefore briefly analyzed the ethical implication these differences have for the idea of openly disputing with patients in the course of PCC and SDM.

Our main conclusions are threefold: First, the case of children indicates that fragile patient decision competence implies more risks of harming patients, counteracting the goals of care, and undermining rather than empowering their abilities, by applying standard approaches to PCC, such as a 'high level dynamic' SDM that may include open disputing of the patient's views. Alternative approaches that have been suggested, provide less room for open argumentation between the HP and the patient, thus weakening the reason for HPs to be prepared to dispute patients. Second, in the public health context the use of PCC methods to, for instance, control and restrict the use of antibiotics in a stewardship program, would not seem to endanger the core values cherished by standard PCC. In spite of the fact that public health pursues rather different and potentially conflicting values to clinical healthcare, the notion of employing PCC – and in that context being prepared to dispute patient beliefs, preference, and values – in order to persuade people to contribute to important public health aims does not imply any disrespect for patients as persons, or that the standard PCC aims are counteracted or undermined. Rather, the situation is similar to the case for disputing with patients in the standard PCC setting, but now with reason for some caution in view of the risk that doing so may not be effective to produce the desirable behavior from a public health standpoint. Third, the more compulsory areas of psychiatry, especially forensic psychiatry, in contrast, do not provide much room either for the notion of PCC, or for the idea of openly disputing with patients. The entire context is essentially coercive and aimed at having the patients comply with external standards they often do not share, necessarily making the

relationship between the HP and the patient one of adversity. A HP may, of course, correct false beliefs of patients about how the system works. However, this has nothing to do with any kind of attempt to adapt the care setting to the patient's personal situation, but merely serves to control the patient while waiting for the type of behavioral change that is externally defined as treatment progress and may eventually lead to release. For that reason, open argumentation also brings risk of undermining such progress, due to the risk of inducing aggressive conflict. This risk does not seem to be manageable through communication training as it may be in the standard PCC setting, as the forensic psychiatric setting means that for the patient to object to care is both rational and natural.

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