Exclusion, Engagement, and Empathy: Revisiting Public Discourse from a Communication Perspective

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ABSTRACT
The idea for this special issue arose from years of multidisciplinary exchange on participation and communication in technology and medicine. Which epistemological, normative, and empirical questions do arise, when endeavors of public participation deal with rejection, skepticism, and critique? This question guides our multidisciplinary perspectives. The empirical examples and theoretical accounts point out that moral justification and social effects of deliberative techniques are as controversial as the question of how to deal with moral dissent. Comprised of five interdisciplinary accounts and followed by two comments, this collection offers a complex picture of deliberative processes. These accounts show that discourses at the intersection of academia, policy, and public institutions tend to render skeptical positions as irrational, personal, or uninformed attitudes, countering them with different techniques. These techniques, so our underlying hypothesis, can be clustered into three types: exclusion, engagement, and empathy. Consequently, the papers ask which prerequisites are needed to engage in deliberations about science and technology; they analyze what happens when engagement fails due to social exclusion or misrecognition; and they scrutinize the epistemic and moral functions of empathy in deliberative engagement. The two comments summarize these papers from a viewpoint of trust and epistemic injustice.

Idea of This Special Issue

Global phenomena such as vaccine hesitancy following the Covid-19-pandemic have illustrated how public distrust and anti-science sentiments are increasing. Other medical or technological innovations, for instance organ donation, are rejected based on concepts of the body and critique in response to power asymmetries. However, such different patterns of rejections do not only appear amongst 'the public', but also amongst heterogeneous and diverse groups of 'experts'. Rejection, skepticism, and critique, thus, cannot be grounded in science literacy alone but need to be understood in much broader sociocultural and political contexts.

Which epistemological, normative, and empirical questions do arise, when academic endeavors of public participation deal with such rejection, skepticism, and critique? This question guides the multidisciplinary perspectives of this special issue. Comprised of five interdisciplinary accounts and followed by two comments, this collection offers a complex picture of deliberative processes.

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These accounts show that discourses at the intersection of academia, policy, and public institutions tend to render skeptical positions as irrational, personal, or uninformed attitudes, and attempt to counter them with different techniques. These techniques, so our underlying hypothesis when planning the special issue, can be clustered into three types: exclusion, engagement, and empathy.

Consequently, the papers ask which prerequisites are needed to engage in deliberations about science and technology; they analyze what happens when engagement fails due to social exclusion or misrecognition; and they scrutinize the epistemic and moral functions of empathy in deliberative engagement. The two comments summarize these papers from a viewpoint of trust and epistemic injustice. Before presenting the analyses in depth, we will lay out the framework of this special issue by introducing a case, which – from an empirical-ethical perspective – spotlights an occasion where public engagement fails partly due to a lack of empathy.

**Setting the Scene: Choreographed Conversations**

In 2018, the German Ethics Council\(^1\) hosted an event on transplantation medicine in Berlin. Its aim was to discuss the pros and cons of an ‘opt out’ solution, where citizens become organ donors as long as they do not explicitly refuse. Prior to this event, the topic had fueled heated political debates in Germany with the Minister of Health advocating on behalf of the opt-out policy.

The event itself was located in a representative meeting room in the Berlin government district.\(^2\) About 80 people of different ages and social backgrounds attended. The schedule was very tightly timed and lasted for two and a half hours. The speakers included one professor of medical ethics, two professors of law, and one professor who specialized in human genetics. The moderator was also part of the German Ethics Council. The event started with the four speakers presenting arguments for or against the opt-out solution. After each of these four short presentations, the audience was allowed to ask comprehension questions. After three experts’ statements, the ethicist elaborated on the organizational problems in hospitals and suggested that these problems may be the possible cause of insufficient donation rates.\(^3\)

Thereafter, a nephrologist steps to the microphone, which is set up in the middle of the room. She reports on her experiences in practice, which relate above all to the difficult handling of brain death. She points out that, from her viewpoint, brain-dead persons are not to be equated with corpses. She refers to their rosy and warm skin. It is, as she states, difficult for the medical staff and for the relatives to handle such ambivalences – taking organs from a body which is perceived to be alive.\(^4\) She would like to debate this issue in more detail, in order to make room for her experience, and the structural factors attached to it. However, she is interrupted rather harshly by the moderator with the request to express a comprehension question. Later on, the moderator clarifies, there would be room for statements: “Please ask a question”. But the doctor simply replies: “No”. A murmur goes through the audience. The doctor elaborates further on the difference between corpses and the brain-dead. Now the moderator interrupts her and refers to a statement of the Ethics Council on the subject of brain death: “I ask for your understanding that we are not discussing the topic of brain death today, the Ethics Council has commented on it in detail”, the moderator says. Another woman from the audience calls to the podium, but unfortunately cannot be understood. Now the ethicist, who gave the lecture before, joins in and reacts with understanding. From her point of view, it is precisely the experiences of clinicians that should be heard. She understands the contribution of the physician “as a very intuitive assessment […] that shapes the actions of many, which has been swept under the table by a hitherto quite dogmatic treatment of the brain-dead”.

After this closure, the expert panelists all enter the stage again to begin their plenary discussion. After one statement, a discussion of the brain death criterion follows – even though the moderator said before that this issue would not be part of the discussion. One law expert keeps on explaining his view on brain death, stating: “If, like me, one considers brain death to be the death of a human being – for good ethical reasons – then this quiet coercion to make a decision is permissible, even with legal means of coercion. I tried to say why”.\(^5\) After this statement, a middle-aged woman from the audience
shouts: “No, it is not permissible”. She neither tells her name nor her affiliation but interrupts the expert. With a gesture of wiping away with his right hand, the professor replies: “I know your point of view. We're arguing about it, after all. I just see it differently. Just mark this dissent. We'll sort it out.” Since the events of the Ethics Council present both the proponents and opponents of certain issues, it could be assumed that a controversial discussion – also on part of the audience – would take place. It does not.

What does this case tell us, from a communication perspective? It illustrates how ‘dialogue as an ideal form of communication’ (Craig 1999, 139) fails. But why does it fail? Surely, we can find good explanations also in the pragmatics of the situation: the time limit was tight and – according to one position – everything was already said about the topic of brain death. Still, this is not a complete theoretical reflection of what happened at this event.

The sociocultural tradition of communication theory – which sees communication processes “as the (re)production of social order” (Craig 1999, 144) offers us a theoretical lens here: “Communication in these traditions is typically theorized as a symbolic process that produces and reproduces shared sociocultural patterns. So conceived, communication explains how social order (a macrolevel phenomenon) is created, realized, sustained, and transformed in microlevel interaction processes” (ibid.). Starting from here, we might ask which patterns, which sociocultural and moral scripts, we see in the case. First, there is a pattern of expertise, which does not unfold as a deep competence in terms of knowledge and experience – but as a discursive privilege (Linker 2014). The second pattern is a dominance of neurocentrism (Huber and Kuschenko 2009), which still prevails in the field of transplantation medicine, giving full attention to the brain as the central human organ. It illustrates how the phenomenology of donation processes the doctor is referring to – an ambivalence of knowing about brain death, maybe even accepting it, but not perceiving it – is still marginalized in discourses, although it remains a major subject for clinicians, relatives, and organ recipients (Haddow 2005; Svenaeus 2010). The third pattern is the deep meaning of refusal, which becomes visible through the doctor’s clear-cut: “No”. This refusal contains a lot of meaning. Mauss (1967) is helpful here, who in The Gift conceptualized a refusal as a form of cutting social relations – sometimes aiming at establishing new rituals or new obligations. Thus, the last pattern remains ambivalent: viewed pessimistically, the doctor simply refuses to play the language game of the Ethics Council. Regarded optimistically, she wants to change these rules. That way, a refusal is also a request: a request for change (McGranahan 2016).

Jasanoff, Hurlbut, and Saha (2015) point out that a broad concept of deliberative engagement is needed in contrast to the rather narrowed field of expert-policy discussions: “Opportunities for deliberation should not be reduced [. . .] to choreographed conversations on issues experts have predetermined to warrant debate. Confining public engagement exercises to such constrained parameters too easily presumes that the entry card for engendering deliberative democracy is speaking the right language, that of scientific rationality” (ibid., 6). Choreographed conversations are exactly what we saw in the above case. While the patterns of expertise and neurocentrism have been part of organ donation discourses since its start in the 1970s (Schicktanz and Wölhke 2017), the pattern of explicit – public – refusal by a doctor is new. Like a streaker in a soccer game, it was a quick disturbance of the choreography. Like the streaker’s appearance, it did not impact the general course of the event, as the experts continued their discussion.

As the case shows, a ‘choreographed conversation’ leaves little room to negotiate forms of communicated experiences that do not align with shared sociocultural and moral patterns. However – and most importantly – the doctor did not at all claim that brain death is an invalid criterion for death. Rather, she wanted to point out the everyday challenges and problems of a system, which ignores the practical difficulties of this concept, demanding a space besides the choreography to talk about a marginalized topic. Unfortunately, we do not know how the discussion would have developed further had the choreography been changed at this point.
Uncovering how exclusion, engagement, and empathy do and do not occur in ‘choreographed conversations’ is a crucial key to understanding the mechanisms of discourses that offer different possibilities of public participation.

Exclusion

‘Exclusion’, in a very broad sense, means not to be recognized as a person in a specific system. As Herzog (2021, this issue) notes, exclusion can be described as not being considered a relevant partner of communicative interchange, a definition that precisely describes the case presented above. Hereby, it is crucial that “[p]re-linguistic and alternative forms of communication play important roles in regard to the excluded” (Herzog 2021, 2). Consequently, communicative interchange denotes quite different modes of interaction that are not limited to language, which is the most classical (and surely most Western) mode of communication. For instance, gestures, intonation, or positions are also forms of communicative interchange (Hansen and Pfurtscheller forthcoming), which we see in the case by the gesture of the expert ‘wiping away’ the doubts of the doctor. Communication, thus, is an option to demonstrate who counts as an adequate communicative partner, who is recognized and who is not. With Herzog’s definition, a new perspective on exclusion arises, viz. a focus which helps us understand why communication fails: “the excluded is socially hindered from performing competent speech acts or from being considered relevant” (Herzog 2021, 4). From this angle, we can also grasp the consequences of such exclusion processes: “It is often the excluded who have learned that their claims of recognition do not have the same importance than those of hegemonic social groups and therefore hide and stay silent” (ibid., 7). Ethically, this is relevant since human beings are vulnerable to such excluding actions, which might provoke suffering and undermine fair and truly deliberative discourses. It is striking that through communication, as a (re)production of social order, we engage with each other and with the world, and we construct and reconstruct the social sphere (Waisbord 2019, 38). At the very moral and analytical heart of understanding communication as an expression of recognition lies the idea that communication is a practice of care: with whom and how much we communicate, can express our respect and appreciation for others (Noddings 2015). Following this understanding, we need to exceed the pragmatic use of communication to only achieve certain pragmatic or solely strategic goals.

Daukas’ (2006) work on the “principle of charity” in communication is helpful to make concrete use of our general claim. Daukas argues that in the sense of epistemic cooperation, we should criticize another person’s arguments in a way that still benefits our opponent, recognizing the other as epistemically credible and trustworthy: “[i]n order to see one another as potential epistemic partners, or as co-members of an epistemic community, we must presume one another’s behavioral expressions of epistemic authority to be more or less reliable” (ibid., 110). If we do not follow this principle, thus deeming the other’s perspective unreliable, we either risk epistemic misrecognition, a loss of cooperation, or even epistemic exclusion.

Engagement

Engagement in deliberations about science, medicine, and technology is a well-researched topic, focusing on the inclusion of different stakeholders and different forms and levels of expertise within public negotiations and assessments (Schicktanz, Schweda, and Wynne 2012). Scholars conclude that when deliberative formats such as citizen councils discuss the legitimacy of technology projects, they often face the problem of applying a top-down engagement approach (Bogner 2012; Weingart, Joubert, and Connoway 2021). In their discussion of so-called ‘hybrid formats’, Gordon Mitchell, Johanna Hartelius, David McCoy, and Kathleen McTigue (2021, this issue) research a specific technique of public deliberations in the context of person-centered healthcare, which aims at heterogeneous stakeholder engagement. Professional medical actors, policy advocates, patients,
researchers, and activists all gather in a deliberative exercise. The advantage, which appears through their method, is a broad sensitivity and openness to different forms of expertise and attitudes that allows for an analysis of the epistemic functions of deliberative formats (4). Regarding openness as discursively produced, the method regards communicative mismatch and conflicts – as can also be seen in the case above – as opportunities to “tolerate [. . .] a certain amount of productive ambiguity, wherein seemingly incommensurate kinds of experience convene, not in spite of differences but by embracing commonality through communication” (5). Robust social knowledge on contested issues, they argue, requires a “collective learning process” (ibid.) with the experiences of heterogeneous actors informing the decision-making process. The mutual face-to-face exchange of positions, personal narratives, and epistemic openness to other positions changes the participants’ perspectives. Thus, the authors focus on an under-investigated topic in deliberative engagement practices: empowered deliberations which exercise “formal or informal influence on institutional decision-making” (17). Their analysis highlights the productivity and innovativeness of an open deliberative understanding of dialogue that brings together very different epistemologies without shying away from conflict and dissent.

As Hilbrich and Hansen (2021, this issue) show in their empirical analysis of the German discourse on organ donation, the hesitance to realize taboos in medicine and technology creates conflicts and ambivalences for all actors involved. Moreover, the role of relatives in the decision-making process is widely underestimated. People always decide for or against organ donation in the context of social relations. For example, it may happen that the documented will of the patient to donate organs contradicts the wishes of the relatives. In practice, it is always the relatives, who ultimately decide. If one asks the medical actors, this is common practice, which, however, is completely taboo and finds no equivalent in the public discourse. Thus, empirical analysis shows that there is a strong discrepancy between the legal concept of the autonomous subject and the decision-making practices of individuals. The family serves as the central site of negotiation processes and must therefore be integrated into deliberative processes on organ donation. A lack of openness on contested aspects within discourses creates epistemic opacity for all actors involved. The analysis also shows that relatives are often left alone with their grief in a biomedical discourse that focuses primarily on the sick body. Successful deliberative procedures in medicine should therefore rely heavily on the inclusion of different emotional and psychological experiences of those affected. In this case, communicative engagement would first mean – as Mitchell, Hartelius, McCoy, and McTigue (2021) have also analyzed – to aim for openness and to work on taboos. This would prevent negotiation processes from being unilaterally based on abstract concepts that do not correspond to the practice of the individuals. This could also avoid reproducing asymmetrical deliberation procedures that focus too little on the experiences of the people concerned – in the case of organ donation these are relatives but also the medical staff.

Empathy

The case above illustrates how a situation, which was planned as a public engagement dialogue, turns into discursive exclusion. This particular turning point, the ‘wiping away’ of doubts and refusal, is also marked by a lack of empathy. Empathy is the ability to share someone’s feelings or experiences by imagining what it would be like to be in that person’s situation. When we are empathic, we open ourselves to the unique perspective of another person. As Susen (2021, this issue) points out in this special issue, empathy is a “central capacity” of human beings, which is developed through relationships but “also nourished by the perspective-taking processes” (Susen 2021, 18). It is evident, again, that such perspective-taking processes are deeply rooted in our lifeworld: the capacity for empathy is both learned and exercised through communicational acts. In particular, this becomes apparent when we do not follow a traditional model of communication as “a process of sending and receiving messages or transferring information from one mind to another” (Craig 1999, 125) but understand communication as a constitutive and symbolic process that (re)
produces meaning and a social order. There are cases in which we cannot exercise such empathy – for instance, when the other is not directly present and their perspective is only mediated, like on screen. There are other cases, however, where the other’s “frame of reference” (Susen 2021, 19), their situation, feelings, and thoughts are directly accessible for us – and so is our reaction to them. With the communication process, it might be a turning point whether we make use of this central capacity – for instance, by imagining being in the situation of the doctor speaking about her ambivalences on brain death. We see it as a general challenge for the medical system and for deliberative discourses to open up a space where such capacities can be nourished, such as, taking up the anxieties of others, but also through engaging their hopes or distrust as topics of public events, or in local ethics committees and further research projects.\(^7\)

At this point, it is also striking how Janna van Grunsven and Sabine Roeser (2021, this issue) conceptualize empathy. They criticize traditional understandings that see empathy as a way of identifying with another person or group by finding similarities. It is a merit of both Susen, from a theoretical viewpoint, and van Grunsven and Roeser, from an applied viewpoint, that they propose a much wider concept of empathy, which allows for encounters with the unknown, “directed at the other person in her otherness as someone who occupies her own unique perspective onto a world we can nevertheless share, can be found precisely where it was allegedly wholly absent” (van Grunsven and Roeser 2021, 7). In the field of autism, they convincingly argue from an ethics in design approach, how augmentative and alternative communication (AAC) technologies provide a communication technique, which “can help us to rethink empathy as a capacity for relating to others who have genuinely different experiences of the world” (ibid., 2). Again, here, the role of communication as the (re)production of social order is apparent: Everyday communication is not self-evident and possible for all groups in society. And those who communicate, often follow “neurotypical communication norms” (ibid., 4) as part of that social order. Those groups, by their inability to communicate, are marginalized in the social order. Communication technologies, as van Grunsven and Roeser demonstrate, can open up a possibility to re-produce or re-new that order, especially for marginalized or devaluated groups. But again, this depends on the social practices and circumstances attached to the situation.

The empirical examples and theoretical accounts presented in this special issue, point to the fact that moral justification and social effects of deliberative techniques are as controversial as the question of how to deal with moral dissent. Oliver Feeney (2021, this issue) in his commentary highlights how insights throughout the special issue positively relate to the growing focus on generating and rebuilding trust and trustworthiness – rather than just highlighting facts and improving information – in addressing important contemporary societal debates such as genome-editing technologies that need to generate trust, or vaccine use which involves rebuilding trust. Moreover, if engagement strategies fail they risk fostering bad epistemic conduct or – as Leefmann (2021, this issue) shows in his commentary – even epistemic injustice. Therefore, this special issue makes a valuable contribution to the question of how deliberations can succeed, but above all which hurdles and taboos have to be taken into account in order to enable the participation of heterogeneous groups of actors in complex societal debates.

Notes

1. The German Ethics Council acts as an interface between the public, science, and politics. Its task is to discuss controversial issues and draw up recommendations for legislative, academic or societal action. The Council hosts frequent events, which are directed at the public including debates on organ donation. https://www.ethikrat.org/en/the-German-ethics-council/?cookieLevel=accept-all&cHash=1d3cc5092007e28668fb99d0e9206b4707
2. The case presented in the following was conducted as part of the empirical research project “I would prefer not to”. Organ donation between unease and criticism. A sociological and ethical analysis’, which was funded by the German Research Foundation under the grant number 252341816.
3. This point was also discussed in the literature during this time (see e.g., Machado 2019).
4. Shildrick (2010), and others (see e.g., Schicktanz and Wölhke 2017; Nair-Collins and Miller 2017) have shown that this phenomenon is all but a singular and purely subjective experience.
5. What he means, here, is a coercion of possible donors in the context of the opt-out solution.
6. The paper was initially accepted as a regular article in Social Epistemology, but later co-opted into the special issue due to the excellent thematic suitability.
7. Surely, being empathic will not end the ethical controversy about brain death. But this is not the focus here, as much ink has already been spent on this particular topic (Schlich and Wiesemann 2001; Truog and Robinson 2003; Veatch 2005; Singer 2018).

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