Participatory Governance of Healthcare: Centring Dialogue and Interrupting Epistemic Injustice

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Abstract: Traditionally governance is set up to stabilise and control and hold organisations accountable for their actions. Experts, decision-making and privileged citizens close to the centres of power and strategic decision-making determine those processes. Hence, many voices and perspectives are silenced, resulting in mismatches between policies and people's needs. We propose a participatory approach to governance in the field of healthcare where people in vulnerable and marginalised positions are involved through a relational process to influence policies, with the goal of social justice and social change. This requires a communicative space for mutual learning, listening, questioning, and dialogue. In practice, we find that precisely the experiential and pathic knowledge of people in the margins often produces a breakthrough in making contact with policymakers and professionals and interrupts processes of silencing and epistemic injustice. For example, a creative expression in a performance or exhibition leads to a call to action. In our article, we illustrate our approach with a few cases from our practice of an eight-year-long collaboration with people in vulnerable positions, artists, researchers, managers, and policymakers to make a change towards social inclusion in a large city in the Netherlands.

Keywords: Communicative Space, Horizontal Epistemology, Epistemic Justice, Participatory Action Research, Pathic Knowledge, Boundary Objects

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Introduction: Decision Making in Healthcare Governance

Governance entails actions and decisions to monitor organisations and includes decisions that structure expectations and legitimise actions within society. Traditionally, systems of governance are populated by policy- and decision-makers and experts. Nowadays, there is an increasing interest in engaging and involving citizens to adjust policy measures to their needs and lifeworld. 'Participatory governance' refers to democratic processes that aim to involve citizens in public policy making at local level (Gaventa 2003). Comparable notions are 'distributed leadership' or 'collaborative governance', which are relatively new approaches in the scientific literature. Leadership and governance in these approaches are not understood as an individual trait or something being exerted vertically or top-down but take horizontal and collective forms with room for polyvocality, alternating leadership, and mutual influence ('t Hart 2014; Zhu et al. 2018). In collaborative governance more people are engaged in the process of decision making. Instead of one leader there are many stakeholders involved in democratic decision making.

New spaces for participatory governance can be used for transformative engagement, but in the field of healthcare we notice that public and patient involvement is often limited to privileged citizens. For example, several countries have organised citizen summits to stimulate a dialogue on the future of long-term care for an ageing population (Citizen Assembly 2022). There are, however, worries that such measures are tailored to the wishes of a happy few (Van de Bovenkamp et al. 2018). As a result, not all voices are taken into account. Within healthcare governance, this implies that certain groups of patients and their family members are not involved in decision making. At the same time, they are often the end-users of policies and decisions.

Not considering or involving citizens, including those who live in vulnerable situations and are marginalised, is problematic because patients and families have their ideas and perspectives on situations, a perspective grounded in their lived experience and referred to in anthropology as an 'emic' (insider) versus an 'etic (outsider) perspective (Pike 1967). As a policymaker or expert, one can know everything about illness and disability, but this differs fundamentally from the lived experience of being ill or disabled (Carel 2018). In healthcare, patients acquire knowledge based on self-experience; they experience what it is like to be ill or disabled. This experiential knowledge is considered unique because one cannot get this knowledge without undergoing the experience (Dings and Tekin 2022). By involving patients in governance, healthcare can introduce this perspective, so that knowledge and decisions align with patients' lifeworld and contribute to their quality of life.

Another argument for why it is crucial to include patients and families in governance systems is value-laden: patients and families have a democratic right to be involved in governance because their interests are at stake (Greene 2006 in 't Veld 2010). They are often the intended end-users of decisions, so why should they not be co-determining the policies and decisions that address their lives? If they are excluded from decision making, they cannot bring their values and interests to the fore. To date, governmental bodies and supplementary boards have determined decision-making processes. Patients and their family members hardly participate in this and are therefore excluded from the processes of decision making (Crawford et al. 2002; Ocloo et al. 2021). We argue that patient participation is essential; having a say and being heard has value in itself, quite apart from the outcomes. Having a voice means recognition, and this is in and of itself important to human beings.

As pointed out above, the chances to engage in citizen participation at local level are not equally distributed. Intersectionality offers a useful lens for understanding how the multiple aspects of identity and multiple systems of oppression interact with each other to shape people's lived experiences and hence the opportunities to participate in policy making. Intersectionality assumes that various forms of oppression are connected. Lately, intersectionality is receiving growing attention from scholars studying (health) inequities (Crenshaw 2017; Hankivsky 2012; Verdonk, Muntinga, Leyerzapf & Abma 2015). For health scholars, intersectionality provides a framework to understand health inequities within and between groups, to identify groups who are specifically at risk, and to understand how these health inequities are shaped by the broader societal context, taking into account societal systems of oppression, including class, ableism, and racism.

In the rest of this article, we will outline our vision of participatory governance in healthcare. We first set out to argue why dialogue and deliberation should be central in governance, relying partly on the theory of communicative action outlined by the German philosopher Jürgen Habermas (1985), and those who criticised his work for being overly rationalistic. Next, we therefore foreground theories on marginalisation and explore how power might interfere in vertical governance systems through silencing and epistemic injustice (Fricker 2007) and what is needed to centre dialogue and deliberation. We introduce a practical example where a horizontal system of governance emerged and present a few cases from our practice of an eight-year-long collaboration with people in vulnerable positions, artists, researchers, managers, and policymakers to make a change towards social inclusion in a large city in the Netherlands.

Centring Dialogue and Communicative Space

Habermas (1985) provides a useful framework to understand our modern society, the roles of systems of governance, and the need for what he called 'communicative spaces'. Habermas has been critical of modern society and dehumanisation and looks for a new foundation for democracy in the dialogue between citizens and in the openness of the equal exchange of ideas and arguments between people. Habermas sees a lack of communicative action due to the imbalance between the system and life world and the dominance of strategic action and power struggles between people. Habermas (1985) assumes that the system logic and related forms of bureaucratisation and market forces can be tamed and normatively controlled by the lifeworld and communication action. He therefore pleads for increasing the dialogical space and develops a theory of communicative action as the basis of his vision for a more humane society.

In line with Habermas's analysis, we argue that governance and evaluation or accountability systems are often structured and based on system values and norms, relying heavily on expert knowledge and functional reason (Woelders & Abma 2016). Following Habermas's analysis of our modern society, there is a risk that the imbalance between system and lifeworld will be further increased through governance systems and that certain types of action and certain voices and values are systematically under-represented in governance systems. Crucial in the context of governance, then, is the critical awareness of the constraints arising from hierarchical relationships and the use of language that enables all participants to understand the arguments and values that support different validity claims and the expression of experiences and opinions. Only then is an honest dialogue possible in which participants dispute validity claims through conscious argumentation, acquire moral insight, and jointly give meaning.

According to Habermas communicative action forms the basis of everyday communication between people in their lifeworld, in which people try to reach an agreement with each other. It is a place of 'mutual acknowledgement, taking a mutual perspective, a shared willingness to see one's circumstances through the eyes of the stranger and to learn from each other' (1985, 291). In communicative action, people can express their inner selves and be authentic, according to Habermas. Furthermore, communicative action offers the possibility of expressing social relationships and relationships and raising questions concerning those relationships. Finally, communicative action aims at truth and offers space for all to make assertions about reality and test them through deliberation and dialogue. This means that people check with each other: Is this true? Is it sincere what someone is talking about? This refers to good reasons and arguments that people make and put forward and goes beyond

yes/no positions. In other words, for Habermas, social reality is a product of communicative action, and a shared understanding can arise between people in co-creation.

To make communicative action possible, Habermas outlines several conditions: a) the voluntary nature of being convinced; b) the ability to contradict, say 'no', express doubt, and introduce new paradigms; c) the absence of power differences: no one should be silent because of hierarchy or sanctions; and d) the space to express oneself honestly (no manipulation). Under these conditions, Habermas believes that it is possible to have a power-free communication (*Herrschaftsfrei Communication*) and to arrive at a rational consensus.

However, we want to go a step further because his work has been criticised precisely on this point – the Enlightenment belief in the rational actor and that rational communication and argumentation will generate social and moral unity. For example, postmodernists such as Francois Lyotard (1988) and Iris Young (1990, 1997) have pointed out that power interferes in communication and that exclusion is inherent to speech acts. For example, people's silence does not equate to agreeing with specific arguments. Sometimes people do not explicitly say 'no' to what they find objectionable, but they simply do not see the possibility of putting forward their considerations because these do not fit within the dominant discourse. So, while Habermas (1985) still believes in rationality to come to agreements, postmodernists show that power is always at work and interferes in more or less subtle ways than Habermas envisioned in his work. Moreover, these critics point out that not everything can be expressed in language and that there are sources beyond rationality to realise moral bonds such as emotion, embodiedness and care. In the next section, we will expand this argument by bringing in the notion of silencing as a form of power and exclusion. In the rest of this article, we will therefore foreground theories of oppression and marginalisation.

Silencing and Epistemic Injustice

Indeed, power inevitably interferes with governance and determines which voices are valued or not and, thus, which knowledge is valued. Privileging scientific evidence as the gold standard and highest form of knowledge in the field of healthcare, which is heavily influenced by the standards in the biomedical sciences, is one of the reasons why in systems of healthcare governance, lay people and advocacy groups – those who are not experts and who hold less powerful positions – will find it harder to have their voice heard (Barnes 2008; Strathern 2000; Yanow 2003; Young 1990). Their knowledge can easily be disregarded as 'just another anecdote,' 'an emotional outburst,' 'subjectivist,' or 'irrational.' These processes, therefore, prohibit accurate

balancing of values and are at risk of becoming narrow and superficial when countervailing powers are excluded.

The concept of silencing is helpful here to understand how power and the processes of inclusion and exclusion work. Silencing goes beyond denying someone the mere opportunity to speak but involves contesting the validity of one's statements. In other words, the speaker and the story are already disqualified as unreliable even before something has been uttered. So, it is not about moments when individuals are silenced but about the structural dimensions of silencing certain groups of people. This exclusion can take many forms, such as mocking someone, dismissing experiences as 'just' anecdotes or hijacking a conversation. One should be aware of the effects of being structurally negated and ignored. People who are over and over given the impression that their language or culture does not fit, or who repeatedly hear that their education is not appropriate will lose their own story and self-confidence.

What follows is an example illustrating how silencing can work out. We were involved in a participatory study with older people, in which well-educated older men with a career were always the first to speak and were long on substance so that the women did not get chance to speak. This had everything to do with habits and gender relations. The researcher tried to point out to the men that in a democratic process, everyone has a voice, but it proved difficult to break through that dynamic. You consider this perfectly normal if you have always been given plenty of space to talk. If someone points out that you are thereby limiting the speaking possibilities of others, it can feel like an infringement of personal freedom. In the end, communication space was only created for the older women when two men decided to withdraw; the process of silencing was interrupted. From that moment on, the women began to articulate their voices (Bendien, Groot and Abma 2020).

Knowledge is also silenced because not all people are proficient in language or can speak it coherently. This includes people with cognitive disabilities. Our academic methods assume that participants are autonomous speaking subjects, and that people can voice their needs and wishes. This leads to a large group of, for example, older people with dementia or speech limitations being systematically under-represented (Groot, et al., 2023). Backhouse and colleagues have expressed how older people with cognitive disabilities are systematically written out of research that causes their voice to be lost, and call on future researchers to make room for these voices:

> Residents with cognitive difficulties were often screened out from studies or only informally involved. If involved, cognitive difficulties could greatly restrict residents' involvement. Future research should

explore the best ways to involve residents with cognitive difficulties in studies, so that their voices can be heard. (Backhouse et al. 2016, 337)

Finally, there is much that is unspeakable and cannot be expressed in words. This knowledge is left out of dialogues. This often involves experiences of love, pain, and suffering. For example, we noticed that women, most of the time single mothers with children with a disability or psychiatric vulnerability, who had grown up in a lower-class family and nowadays living in poverty all had lived experiences with various forms of abuse and violence, stress, financial debts, and unemployment (Groot et al. 2022). Initially, the women did not speak about these experiences and kept them secret; it was too shameful and too difficult to share and thus remained invisible. Only after a few years of research on poverty and health promotion, with the help of arts-based and creative methods (Groot and Abma 2020), did they feel at ease and shared their experiences (mostly) non-verbally. Creative methods were helpful to express what can hardly be put into words. In this case the women received fake money to imagine how they would spend millions of euros (see figure 1). In their images and dreams they envisioned the support and services needed to solve problems related to their socioeconomic position. This perspective differed from the focus of professionals and policymakers on lifestyle interventions. The women brought something to the fore that could not be articulated and expressed in the policy discourse on self-sufficiency.

A similar situation emerged in a study surrounding people with learning disabilities. In a study about community care, they told us they were often the informal carer for their parents or people in the community. One client told us, 'I help my father. He has been in hospital – two broken knees. So, I clean his little house. Every day.' Others offered practical help in the neighbourhood: 'We put up this fence. Very sturdy. For that little neighbour. Yes, she's 90...'. These informal care tasks were barely heard and acknowledged in a professional dialogue session at the end of the study. The idea that people with intellectual disabilities were not only care-receivers, but could be caregivers as well, simply did not fit in the prevalent discourse and stereotypical imagery of people with intellectual disabilities. Professionals mainly talked about the care and support they could give as experts, not about the value of these people to the community.

Here we see how dominant discourses structure the debate and determine what can be said, and by whom, and thus who and what counts as valid knowledge. Not all that is said in the communicative space can be heard, can be understood, or can contribute to mutual understanding and new insights (Woelders 2019). Philosopher Harry Kunneman (2017, 16) describes this as follows:

> The situation, in which the dominant discourse, for example a thera-peutic discourse, colonises the communicative space and absorbs all that is said in its own conceptual framework and defuses it. What has to be said and might be said, lets itself not be said. The words are lacking, or are, when they come, are absorbed in a space of meaning, that turns them into strangers. Into uninvited strangers, who only can be admitted when they get rid of their strangeness after an integration course... And, the question is, whether there is a language available for what is experienced or felt.

Mutual understanding is only possible if there is a language available to express meaning (Woelders 2019). The above examples illustrate that not all experiences can be expressed in the existing and dominant language (fitting the dominant discourse) and that what cannot be understood in the dominant discourses runs the risk of being absorbed and reduced to the dominant discourse and may therefore get dismissed.
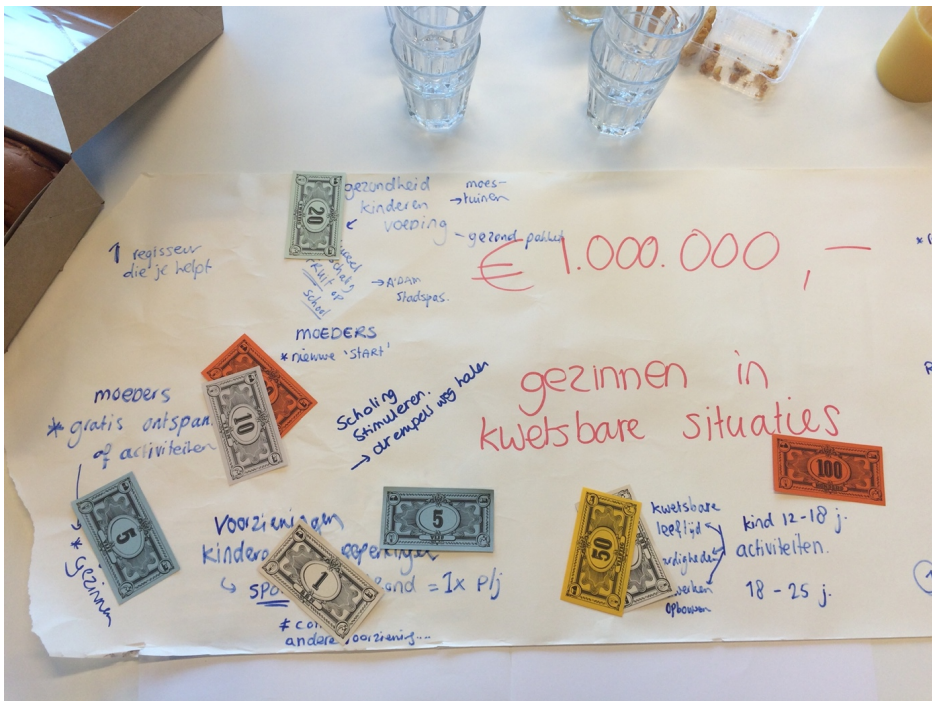

Figure 1: The game about investing money for the social good of mothers living in poverty

These processes of silencing lead to epistemic injustice: 'In all such injustices the subject is wronged in her capacity as a knower. To be wronged in one's capacity as a knower is to be wronged in a capacity essential to human value' (Fricker 2007, 5). If patients and families are not recognised as 'legitimate knowers', they are denied a fundamental human capacity. This has ethical, political, and epistemological consequences. Not involving the patients and families in governance affects their human dignity because they do not receive recognition as a knower of the world. On a political level, this means that people do not see their interests represented, leading to anger and frustration or complete withdrawal from society. On an epistemological level, there are concerns over the (in)completeness of our knowledge of the world: if the perspectives of those without power in our social world remain unheard, our collective knowledge resources are less robust. If those without power are silenced, this leads to an incomplete and inaccurate understanding of the social world.

Toward Participatory Governance

To make our governance practices in healthcare more inclusive and participatory, we can deliberately create and facilitate communicative spaces where all stakeholders and citizens are able to be involved. As pointed out in the examples above, this requires academics to facilitate these processes that acknowledge the limits of their verbal communication and the willingness to interrupt processes of silencing and epistemic injustice. In our practice, it has proven helpful to work with welcome rituals to acknowledge people, to create and value silence for those who are less verbal and assertive, to create safe spaces and to use artworks and creativity and all the senses to understand the ways people communicate. Precisely because power and silencing processes interfere, this is a precondition for shaping the joint moral learning process by building in joint reflections on the process of cooperation. This requires a process of reflection, a care-ethical attitude, and an ethos of attentiveness, empathy, and solidarity (Groot et al. 2018).

Participatory governance starts with rethinking the underlying epistemology in governance. This epistemology can be described as vertical, in which the expert stands above the layperson, objective above subjective, and rational above emotional. The pyramid of knowledge is its symbol. Participatory governance requires recognising epistemic plurality (multiple forms of knowledge) and more horizontal knowledge systems (coexistence of knowledge forms). A horizontal epistemology values scientific knowledge, but this epistemology gives equal value to practical-professional knowledge developed by practitioners in their practical work, as well as to the experiential knowledge of patients and families as a form of valid knowledge; and it values artistic-creative forms as expressions of knowledge that cannot be said or expressed in words (Abma 2020).

Horizontal epistemology means giving up the ideal of a firm or absolute ground in the process of knowledge production; there is no meta-theory to distinguish various forms of knowledge, and researchers are always interwoven with the phenomenon of study, as are other stakeholders. Therefore, our desires and agenda always permeate our view of the world. A horizontal epistemology acknowledges that there are some laws to explain natural processes but also many unpredictable aspects of reality. This includes the acceptance of the friction between facts and values. Within a horizontal epistemology, co-creation and narrative sources of knowledge are preferred. Furthermore, there is the acceptance that wicked or messy problems demand our attention and are not easy to fix and tame. While many researchers may prefer to avoid these problems by focusing on easy-to-manage and controllable conditions (RCTs), we argue that more qualitative and participatory research is needed to deal with these kinds of problems.

In participatory research and related methodologies, the aim is to enhance the personal and mutual understanding of people whose life and work is at stake as a vehicle for collective action and local improvements (Abma et al. 2019). Respect, inclusion, democratic decision-making, mutual learning, and collective action are the main principles of participatory research (ICPHR 2013). Control and decision-making power are shared between the researcher and people whom they concern. They are the ones to define the research topic based on the 'pressing issues' in their lives. Their role becomes one of co-researcher, and as co-researchers they are involved throughout the whole research cycle from formulating the goals and questions to the analysis and sense-making and sharing for knowledge. The role of the researcher is to facilitate a dialogue among and between groups of people.

Case Example

An example of a participatory governance initiative in which dialogue and reduction of epistemic injustice were central was the platform Centre for Client Experiences (in Dutch Centrum voor Cliëntervaringen). In 2015, a small group of people with a shared mission to improve the quality of care by participatory health research (PHR) started the initiative of a learning platform. The initiators were the authors of this article, based in academia, and the director and researcher of the client advocacy organisation. We called members of the platform 'partners'. All platform partners were striving for change within their context but felt alone in their mission. They often experienced resistance in their context and were looking for partners who shared their mission. Partners were embedded in different settings of care and well-being; they worked with healthcare providers, municipalities, research funding, client advocacy organisations or charity organisations, and universities. Above all, a group of people with lived experiences were full partners in the Centre from the

moment it was established. These people have lived in vulnerable situations, reflected on their lived experiences with others in a comparable situation, and were eager to make a difference for themselves and others in a similar situation.

The development of the Centre was based on the ethical principles of PHR: democratic participation, equality, respect, inclusion, and mutual learning (ICPHR 2013). It was a place where a core group of people could learn about participation collaboratively and in dialogue. By sharing stories, and precarious experiences and reflecting on shared situations, the Centre offered a space to learn and develop competencies in participatory research. For five years, we met four times a year for 'collaborative learning sessions.' In these sessions, we developed a shared mission and vision and established key values that we all see as crucial for collaboration. In many of these sessions, we used creative methods and materials to enable anybody to join the conversations, such as poetry, collages, and *tableaux vivant* (see Figures 2 and 3).

Figure 2: *Tableau vivant* in one of the Centre sessions about vulnerability

Figure 3: *Tableau vivant* in one of the Centre sessions about dependency

Multiple stakeholders were involved and challenged to think and express their vision on the participation and involvement of clients. These people did not meet each other regularly, and thus the process helped them learn more about the perspectives of others involved. It was particularly beneficial that people at higher policy levels, such as CEOs at the municipality and healthcare organisations, met face-to-face with patients, family members, and people from the work floor because these worlds are often disconnected. Gradually, they developed a need to explore together what good participation meant and what was needed to improve the position and care for clients. Building trust in each other was crucial in this process of joint dialogue. We have to note that this was not always a smooth process; there were tensions, participants were not always reflective, could not always find the words to express themselves, and sometimes found it hard to listen to alternative views. Yet, it is precisely the willingness to be engaged in these processes that transformed people.

Between 2014 and 2020, the Centre network grew to include ten organisations as official community partners and 20 community co-researchers. This was not planned; it emerged from the process and explicit questions from participants. The co-researchers involved in the sub-studies were invited to participate in the learning sessions, which also became a community for co-researchers when a study was fin-

ished and co-researchers wanted to stay connected. In total, we conducted eighteen sub-studies using participatory research, including interviews and group sessions (n=404 patients) on patient experiences with psychiatric care, community care, day-care, public health, and social work. All studies ended with dialogue sessions (n=367 professionals and directors in healthcare and social work, municipality civil servants, and funding agencies). These studies mostly focused on the evaluation of care policies and austerity measures that were introduced in The Netherlands in 2015 and focused on self-reliance and the substitution of formal care by informal care. The stories of many clients and informal caregivers countered the notion of self-sufficiency and pointed to situations where people do not have a social network to rely on and are simply not able to take care of themselves (Groot et al. 2022). A few quotes from people in those interviews:

> 'If he came to help clean up my house now, I would not mind. However, the way my house looked before, I didn't want to receive my father. I was terribly ashamed of that.' (A young man with a psychiatric vulnerability)

> 'I find it difficult to involve them [family] in my request for help. I find it hard to show that I'm doing badly.' (A middle-aged man with a psychiatric vulnerability)

> 'I do not want to bother my children. When they come, I talk about cows and calves (...) If I have a down moment, I go to the park. (...) I was always a model mother. And now I have to go and ask for help? (...) I have my pride for that (laughs), and you do have to maintain that air.' (An older woman with a psychiatric vulnerability)

In these dialogue studies, we noticed that talking and sharing stories often reproduced epistemic injustice. People with lived experiences felt that their story was not always heard because it did not fit into the dominant discourse. The policy discourse focused on self-sufficiency and those stories, like the ones above, that did not fit into the frame were simply ignored. Policymakers tended to reduce those narratives and its narrators into *unwilling* subjects. In other words, what people experienced was reframed: not a matter of not *being* able to take care for oneself, but a matter of not *willing* to take on responsibility for their own lives. Besides this inability to see inequality, we also observed that policymakers and professionals focused on 'positivity.' So, those who were invited to the policy table needed to speak in positive terms about their lives and work. It was hard for policymakers to relate to those stories that showed a counter picture to the idea of self-sufficiency, and such stories were easily put aside as not 'constructive' (Duijs et al. 2022).

While stories or reports were easily dismissed, when we shared the findings in more personal arts-based products, the team felt a more in-depth impact. Dialogue after a theatre performance, meditation, and art exhibition, created by co-researchers with lived experiences about their understandings, was experienced differently than written reports. The co-researchers were mostly positive on the approach. A person who participated as co-researchers: 'No, it was nice to contribute in everything. Yes, how shall I put it simply: in the final product. (…) It gave satisfaction for myself, and yes, it was nice…To participate in this.' Another participant: 'What struck me [in the relationship between policymakers and we as clients] was that we felt one, it was not us vs them. Not in my experience. Because of their reactions [to our product presentations]. This has already started from the first presentation. It felt very human. A human approach.'

Most policymakers were moved by the presentations of the co-researchers and became inevitably involved in the themes they expressed. A policymaker (July 2018): 'Thanks for sharing your feelings and thoughts with us. We have learned a lot from this meeting. All products were powerful and have affected me.' Another policymaker (July 2018): 'What do "they" think… if they lived in a country without social welfare, they could all work. The city needs people who work! If they can do this… they can also work…' (Groot et al. 2020). A CEO: 'It affects me when I hear a client who says, "But I also belong to society, don't I?" That sort of appeal, that's why I do my job.' (See Figure 4.)

One of the participants also shared a reflection about the process in the group. At first, they felt like a victim in their position as client, but after a while the group transformed and even felt like a group together with the client managers against the bigger system, not against the people in their role as client manager. A participant said, 'It's nice though. At first, we had a lot of angry stories about the client managers and were a bit more victims as a group. During the process, this transformed into more of us together as a group with the client managers having to fight the system together. That was a beautiful process. You can also see that in the expressions. Those of the first presentation. And those of later ones'.

Figure 4: A partner with lived experiences and one with management experiences in a session

Those directly affected, patients and their families, contributed by bringing in 'pathic knowledge' (Van Manen and Shuying 2002). The term pathic is derived from *pathos*, meaning 'suffering and also passion' (220). Pathic knowledge refers to knowledge and understanding that are not cognitive, intellectual, rational, or technical but relational, situational, physical, and action-oriented (219). This is the understanding achieved by putting yourself in the shoes of another (empathy) and by feeling what the other is feeling. We saw this reflected in the statements made by the officials when they became aware of the artworks of people without employment and in the statements made by the CEO that he feels touched by a client who wonders whether he counts in society. We have found that pathic knowledge is more challenging to represent. Our rational and cognitive modes of expression hardly allow this kind of knowledge. As a result, pathic knowledge is easily overlooked or ridiculed in strategic discussions that are often verbal and argumentative in nature (Barnes 2008).

Therefore, we started looking for other ways to express the unspeakable and make room for silent voices. In that search, we came to art and creative expression. We have illustrated that people can open up, listen, and be moved by using art and creativity and by touching the senses, revealing atmospheres and states of mind. Listening to a personal story, seeing a collage, hearing a poem, or experiencing a piece of

music or a dance performance can appeal to people; policymakers and administrators can be touched on an affective level as human beings and feel connected again and show solidarity. In those moments, the shared humanity between people emerges again, and moral insights arise. Such enriched and more inclusive communicative actions restore the balance between the system and life world and lead to new moral understandings, for instance, on the inclusion and exclusion of people who live in vulnerable and marginalised circumstances.

Discussion

Dialogues in governance are often exchanges of words spoken by articulate people. In practice, many people are less eloquent or deal with experiences like illness or trauma that cannot simply be put into words and are easily reduced to the dominant discourse. This illustrates how power interferes in communicative spaces and determines who can speak and what can be expressed and thus what is included or excluded from governance. Hence, their voices remain hidden, leading to mismatches between policies and people's needs. This article proposes a new way of governance, namely participatory governance, with attention to acts of silencing and epistemic injustice. This governance goes beyond the questions about citizen competence (Fischer 2012). Participatory governance creates space for people in vulnerable positions to be involved through a relational process from A to Z to influence policies in a way they are heard and seen (testimonial justice) and facilitated to analyse their experiences and share them (hermeneutical justice). In order to build such a participatory governance process, it takes time and energy to build capacity, create communicative spaces for mutual learning, listening, questioning and dialogue, and use artistic and arts-based methods.

We have shown that creating a space for the voices of patients and their family members in the field of healthcare governance offered them a starting point for finding and expressing their voice and could thus be empowering. Yet, we also experienced how the voices of patients and next of kin could be silenced by professionals and policymakers. This was not just unwillingness to listen to people, but also due to complex dynamics related to the interrelation between power, language and knowledge (Kunneman 2017; Woelders 2019). Dominant policy discourses determined what could be said and understood, and what not. Moreover, some people were granted the authority to participate and speak up, while others were not granted that authority simply because they were seen as being unreliable due to their conditions. This implies that if we create communicative spaces for participatory governance we always need to be alert to acts of silencing and disempowerment (Bendien, Woelders & Abma 2023). Our experiences are also an invitation to create spaces for the

emotive, embodied, and complex modes of existence because people we work with are more than just rational actors as human beings.

Acts of silencing and marginalisation can further be understood from an intersectionality perspective (Hankivsky 2012; Duijs et al. 2022). We have shown how gendered inequality can lead to a situation where men are thought to be superior to women and influences who can take the floor and who cannot, and thus determines who is granted with authority to speak and what can be said and counts as knowledge. In the example of the single mothers, several dimensions of disadvantage (gender inequality, unequal socioeconomic positions) led to a situation of silence and invisibility. Several examples show how ableism is at work in the process of knowledge production and governance in health care. It is simply assumed that all people have healthy bodies and minds and that they can properly speak up and voice their concerns. The examples clearly show this is not the case for people with intellectual or cognitive disabilities, chronic illness, and stress.

Furthermore, we need to be aware that as facilitators of these processes we need more than analytical skills. Yet, there is not much attention paid to the role of the facilitator in these participatory governance processes (Escobar, Faulkner and Rea 2014). As a facilitator, you need to be able to shift gears at many levels: those of administrators, managers, practice professionals, as well as of people with interesting stories and experiences. For example, it can be challenging to initiate the process of mutual story sharing by avoiding horizontal violence in groups where people with lived experience do not have 'space' to listen to each other (Groot and Abma 2020). This often requires emotion and relationship work, also called 'ethics work' (Abma 2020; Banks 2016; Groot and Abma 2022). Ethics work cannot be outsourced or placed outside the organisation; it is inevitably part of governance, accountability, and evaluation research (Abma 2020). Creating a communicative space where all voices are heard may generate ethical knowledge on moral dilemmas as part of participatory governance.

When thinking from an ethics of care philosophy, creating a communicative space is essential for all involved, not just those in vulnerable positions. Sometimes, professionals who put their heart and soul into their work may feel attacked by pathic knowledge expressed by patients and families that affects them (Abma 2022). It can be scary to confront the boundaries of one's professional expertise and control and face complexities that cannot be fixed or tamed by technical solutions. That is what patients and families often share: that they feel left alone with the existential questions of illness, suffering, pain, and death. This requires a redefinition of professional practice that goes beyond the mere application of protocols and handbook knowledge. Professional practices always have a solid hard ground, according to Donald

Schon (1987), but also include 'swampy lowlands' where one is faced with uncertainty and unpredictability. Dealing with this (moral) messiness includes the acceptance of making mistakes and (moral) learning, the search for creative paths to work around the system, and the importance of 'craftmanship' to deal with messiness. Participatory governance creates a space to foster such (moral) learning and reflection-in-action (versus vertical accountability).

The role of less verbal and creative techniques in governance has yet to be discussed in depth. Recently, Carrick and colleagues (2022) stated that one of their practical criteria for effective participatory planning and decision-making processes is diverse and creative methods of engagement to encourage participants to contribute. This is linked with the idea that creative methods could stimulate a communicative space for all involved, especially people in a marginalised position (Groot and Abma 2021). Outside healthcare, there are some examples of creative approaches for participatory governance. For example, Davis and colleagues (2022) called the role of a facilitator in creative, communicative spaces 'the art of invitation', a term coined by Ruth Ben Tovim, Lucy Neal, and Anne Marie Culhane. Facilitators in the 'art of invitation' give themselves a role as boundary spanners and space holders in which an exchange can occur between stakeholders, including citizens, in creative ways. Creating this affective atmosphere (Anderson 2009) can help to learn together in an effective way instead of a functional and efficient way.

Our world is getting more complex, unpredictable, unstable, and uncertain. We face crisis after crisis, and the question can be raised if we will ever eliminate crises. There are signs everywhere, the ecological crisis is perhaps the most urgent, that control, growth, and consumption are reaching their boundaries. Although our world has changed dramatically, we still use vertical governance systems. Vertical governance is, however, not very appropriate when it comes to dealing with this messiness. The messier and more complex, the more we need self-knowledge, dialogue and craftmanship as the basis for moral development in horizontal relationships. This means we must interrupt hierarchic relationships, absolutist moral claims and vertical epistemologies. Horizontal and participatory governance is a new way to learn to embrace the complexity of ourselves and our world, inviting all the voices, pearls of wisdom, perspectives and values needed to build and envision an inclusive, human, and ethically rich future (versus materially rich).

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