



Ethics work for good participatory action research

Engaging in a commitment to epistemic justice

Tineke Abma

Aanbevolen citeerwijze bij dit artikel

Tineke Abma, 'Ethics work for good participatory action research',
Beleidsonderzoek Online september 2020, DOI:
10.5553/BO/221335502020000006001

Introduction

Contemporary societies wrestle with highly complex issues including the COVID-19 pandemic, health disparities, care for the elderly, poverty, polarization and climate change. Yet researchers and policymakers still tend to approach complexities in a linear and mechanistic fashion and place ourselves outside these complexities as if we are not part of the 'problems' and 'solutions' (Alvarez-Pereira, 2019; Schwandt, 2020). Paradoxically, in theory we embrace holistic models of the world as an interconnected whole and acknowledge interdependencies, but again and again we fall into the trap of reducing instead of embracing complexity. Our human challenge is to keep complexity in focus, including moral complexities, and remain reflexive of our desires and attempts for one-dimensional solutions and large-scale planned transformations (Kunneman, 2020).

One way to move forward is by increasing awareness that we need other epistemologies and new ways of relating to our world. In their strive to be democratic, inclusive and impactful, researchers and evaluators search for ways to be more responsive to ambiguities and the needs of various stakeholders, and to actively engage them in the co-creation of knowledge for social change (Abma et al., 2019a; Bradbury, 2015; Fetterman et al., 2018; Van Lieshout et al., 2017). Dialogue and deliberation among stakeholders, including citizens and service users, are seen as ways to mobilize various sources of knowledge, including experiential and artistic representations, to

address pressing issues in local settings. These approaches include ‘unheard voices and angles, avoid[ing] confrontations leading to binary dilemmas, absorb[ing] from all wisdoms and contribut[ing] to making sense of the world in a different way’ (Alvarez-Pereira, 2019: 10).

The heightened interest in citizen science and responsive, participatory and action-oriented approaches among researchers, policy makers, programme planners and funding agencies, is a welcome trend. I see this as a stimulus to rediscover valuable research and evaluation traditions from the past, to generate discussion on current issues (epistemological, methodological, socio-political, existential and moral) and anticipate future challenges and perspectives.

Participatory approaches to research are grounded in ethical principles of respect, social inclusion, democratic decision-making and mutual learning, and thus have normative intentions (ICPHR, 2013a; 2013b; Abma et al., 2019b; Banks & Brydon-Miller, 2019; Van Lieshout et al., 2017). What interests me are the moral complexities of the emerging participatory research and evaluation practices that cannot be tamed by professional codes of conduct and checklists. A personal story about my experiences with user involvement and participatory action research illustrates what kind of ethical issues may arise in practice. The story shows that participatory action research is not only a technical undertaking, but that its ‘goodness’ is also an ethical matter. The story reveals existential and moral questions that participatory ideals generate when put into practice, and shows that these questions cannot be easily fixed, tamed or solved. They are typically ‘messy’ (Cook, 2020). As researchers we commonly tend to avoid these messy issues, focusing rather on the more easy, manageable and controllable circumstances. Yet, as I will argue, it is precisely these ‘messy’ problems that require our attention because they are often the issues of the ‘greatest human concern’ to borrow from Donald Schön’s words (1983).

Many of these ethical issues go beyond the moral high ground of professional codes of conduct and rule- or principled-based behaviour. Protocols and checklists, such as the Guidance for Reporting Involvement of Patient and Public (GRIPP) checklist for Patient and Public Involvement (Staniszewska et al. 2011), are helpful in many circumstances, but are often not rich enough to help us out when facing these messy moral problems. For these complex situations we need additional resources, like our personal understanding and moral compass, and deliberations in the company of critical friends to attend to these issues (Banks & Brydon-Miller, 2019; Van Lieshout et al., 2019). This requires the researcher to have a caring attitude or ethos (Brannelly, 2018; Van Lieshout et al., 2017; Visse & Abma, 2019), but

also ethics ‘*work*’ – a term I borrow from Sarah Banks (2016). ‘Ethics work’ refers to the labour, toil and distress required to realize meaningful and morally sound participatory research. It entails the effort one puts into seeing ethically salient aspects of situations, developing oneself as a reflexive practitioner, paying attention to emotions and relationships, collaboratively working out the right course of action and reflecting in the company of critical friends. Such ethics work is interwoven and part of everything we do or not do, how we interact with others, and what kinds of relationships we forge in our practice. Sharing this behind-the-scene story can be regarded as a form of ‘ethics work’ in itself (Banks, 2016), and I hope this will contribute to a more public, reflexive culture in the field of participatory research.

A Personal Story on ‘Ethics Work’

Below is a story to illustrate examples of messy problems that participatory researchers face in practice. The story comes from a responsive evaluation study on the emergency care for psychiatric patients in Amsterdam, which was carried out by a mixed team of evaluators and experts by experience who jointly made decisions and collaborated in all phases of the evaluation (Groot et al., 2019a; 2019b):

‘Did you ask the clients?’ The question was posed by the former Director of the client advocacy organization in Amsterdam, Ad Warnar. It was a simple question but one that led to a long, uncomfortable silence in the room full of representatives gathered in the Town Hall. They were discussing the quality of psychiatric emergency care in the city. All of them saw the introduction of Psycholance, part of a new emergency psychiatric care model, as an important step forwards, and this was confirmed by an internal evaluation study commissioned by two mental health institutions in the city and completed by researchers at these institutions. Yet this study did not include the perspectives of the users. This was an eye-opener for the two CEOs of these institutions. The question alerted them to the missing voice of the people they aimed to serve.

Subsequently, I received the invitation from the two CEOs to set up an evaluation of the emergency care from the perspective of service users to complement the internal evaluation. This led to collaborations with four experts by experience to develop a research proposal to genuinely honour their voices throughout the whole process. So we – one of my PhD students Barbara Groot and I – invested in building a solid mixed team consisting of researchers with and without experiential knowledge. Three had been service users in the past and one was a family member of a service user.

All of us experienced the first nine months of the research process as fruitful. We collaborated in the development of the design, and all strategic decisions, and worked together in the process of data generation and interpretation. This included deliberations on who to include and how to involve them in the evaluation study; what we expected from the study as well as the changes and improvements we wanted to generate in practice; who benefitted from the current situation or experienced negative consequences; what the underlying mechanisms were; and who we wanted to inform about our research findings.

After seven months we approached the submission deadline of the report and a pre-planned dialogue meeting with all stakeholders: professionals of psychiatric emergency care, police officers, ambulance staff, experts through experience, users and family members. One week to go. As a research team we felt the need for a full, clear report including a conclusion, and it was important to send the full report to all those invited to the dialogue session. However, only the 'findings' were discussed collaboratively in the team at that time; the conclusion was not. One of us had taken the lead in writing the conclusion to work efficiently given the time pressure, and the whole team had not first discussed the conclusions. All team members felt the pressure to perform and find the right words given the political and strategic implications. One team member with experiential knowledge informally expressed her discontent about this speeding up to one of the team members. This signal led us to organize a phone call with the whole research team (May 2016):

'I see that a few sentences are written by someone who could not empathize with the position of the service user. I feel dispossessed. This is not the conclusion I would draw from this research. Who owns the final version? Who decides? Who has the power to decide the content of this most read, and important, part of the report [the conclusion]?'

In this call another expert by experience mentioned her dyslexia, which she felt excluded her from the writing process. She was dependent on her speech to give feedback on the report. We knew this but in the rush to get the report finished we did not create time to talk with her about the conclusions. She argued:

'I could not make it clear ... My arguments were not understood and I could not write them down like the others. Others gained more influence on paper. Parts of my knowledge have been lost because I speak and do not write accurately. So, some users are ... but not all are heard, or understood.'

We acknowledged these arguments and took them seriously by

arranging extra time to rewrite the conclusions. Also, we arranged another meeting to carefully prepare for the meeting ahead of us. The co-researchers made it very clear that this meeting was very stressful for them, because they would encounter professionals and be reminded of the traumatic experiences they had gone through when they themselves were admitted to the emergency ward. They expressed the need for a safe space, otherwise they would not be able to attend the meeting. This led us to discuss what a safe space meant to them, and what they needed to feel safe. It resulted in the decision to start the meeting with music and a poem chosen by the co-researchers, which was a way to comfort them and share their inner feelings. Starting the dialogue with their music was also symbolic; we literally started with their voices. This preparation re-established the trust within our team. As academic researchers this incident made us very aware of our power to create possibilities for involvement and to determine the process. The dialogue meeting itself was intense, because the perspectives of service-users and professionals clearly differed, such as on the issue of freedom restrictions. It was at this point that the dialogue about the value of patient voices really started, because the perspectives of users and professionals came together.

Several months later, we discovered that the report was not what both the commissioners had expected. Clearly, the users had perspectives on the emergency care in the city that differed from most of the professionals. Although some professionals and managers embraced the report and its findings, others thought of it as 'just' a qualitative study, a methodology that did not need to be taken too seriously. They also questioned the stories of the witnesses, and what they thought of as merely 'subjective' opinions. Also the visual images, collages and drawings made by the service users as part of the study were found to be too provocative. We had carefully and deliberately added these images because they expressed the feelings of users more effectively than words (See Image). Yet we were asked to delete them and to give the report a more positive and neutral tone before disseminating it to the public. All the members of our team had concerns with this request, and we decided to talk to the commissioners to better understand the reasons behind their request. We learned that the CEOs were afraid of the sanctions that external inspectors may take when they read about user experiences. These negotiations took a lot of time and one expert by experience ultimately decided to leave the project because she did not want to take responsibility for the report.

We can see in this story how a process of silencing took place in a participatory project that deliberately intended to include the voice of users (Groot et al., 2020). Silencing is, of course, not unique to

participatory research, but is extra problematic because epistemic justice is a guiding value in this approach. This value commitment implies a moral responsibility for the researchers to create room for all voices and various forms of knowledge (Fricker, 2007). If we leave out certain voices, this not only means we leave out certain people, but it also limits our perspective of the world. Our commitment to epistemic justice led us to engage experts by experience in our research team from the very first beginning. Their perspective was deliberately included in all phases of the evaluation process, and led to new perspectives on the evaluated practice (Groot et al., 2019a; 2019b). Yet some voices were almost lost because of deadlines, accountancy requirements and academic routines, such as writing reports. So even though our study had been set up to capture the voices of users, the credibility and authenticity of their voices were contested, they met with resistance and were not taken into account without our active interference. We had to do ‘ethics work’ to ensure that the ideal of epistemic justice was reflected in our project’s results.

Image: Drawing made by expert by experience



Changing Socio-Political Context

The mental health care context in which we carried out the evaluation has a long tradition of service-user engagement and advocacy. More broadly the call to involve clients and service users in health care, policy and research goes back to the turn of the century in the Netherlands. Since then many studies have been carried out with users to gain a better understanding of their world, and to better attune care to their needs and wishes. The evidence that users have a perspective and other priorities that differ from those of professionals has led in several circumstances to innovations in research and health care (Baur, 2012; De Wit, 2013; Schipper, 2012; Nierse, 2019).

Over the years I have noticed how we often fail to realize the normative ideals we strive for as participatory researchers. My

concern is that we have structured participation and user involvement too much along the lines of our current research procedures and organizational structures, thereby ‘fitting’ users into our professional academic frameworks and norms. In doing so, we run the risk of excluding people who cannot meet our requirements (Voronka, 2016). Gearing user involvement to meet policymakers’ or funding agencies’ requirements carries the risk of pseudo-participation. In such instances, service users are involved in superficial and tokenistic ways, leading to the reinforcement of the status quo instead of more equal power sharing among researchers and users (Domecq et al., 2014). This was exactly what we saw happening in our project; the CEOs requested user involvement but they themselves and their organizations were not open to the perspectives of users. Their experiences were seen as criticism, not as an impulse to start a dialogue between users and professionals on what good emergency care actually means.

I have encountered many users who did not have a chance to be part of decision-making processes in society and were therefore highly motivated to join us. Many experts by experience take pride in being co-researchers. I have seen policymakers encouraging participation and participatory research, and researchers claiming to practise participatory action research. But I have also experienced that participatory research is not easy; that it is more than a technical procedure to collect stories of users. More is needed, i.e. ‘ethics work’, to realize genuine involvement. Participation cannot easily be controlled; it requires a lot of effort as well as a new way to approach the process of knowledge creation and development. This will involve a struggle because current epistemologies are ill suited to creating space for experiential knowledge and the voice of users.

Participatory Work Grounded in Horizontal Epistemology and Epistemic Justice

Together with a group of international scholars I developed a participatory action research and responsive evaluation approach grounded in horizontal epistemology (Abma et al., 2019a). In this kind of epistemology, subject and object are thought of as mutually influencing each other, developing a dialogical and shared understanding of the meaning of situations. We explicitly combine this by acknowledging and engaging the capacities of people whose work and life are at stake, and by bringing in our own personal experiences. In line with the transformational purposes of participatory action research, the aim is to heighten the personal and mutual understanding of the people it concerns (Abma et al., 2019a). This type of research generates another type of knowledge in addition and complementary to the scientific proportional modus 1 knowledge and practical-instrumental modus 2 knowledge; it generates ethical-

relational knowledge that is highly relevant to the moral complexities of our existence and modern world that cannot be tamed.

This means that our work challenges the vertical epistemology in which the all-knowing expert stands above laypersons in the production of knowledge. A vertical epistemology can be characterized as follows: it is the expert researcher who has access to the objective truth through using scientific methods and techniques. Laypersons do not have this access and knowledge and are dependent on experts. In addition to the hierarchy of relations between experts and laypersons, this vertical epistemology values certain human capacities over others, like the hierarchical distinction between 'objective' truth and 'subjective' opinions and the high-low distinction between 'rational' capacities and 'irrational' emotions and intuitions.

This horizontal epistemology can be characterized as follows:

1. It has transformational aims and goes beyond description or explanation: its purpose is to heighten people's understanding of their situations, and to put their 'private troubles' on the agenda of policymakers and professionals. This includes a personal understanding of the way people perceive their world, as well as mutual understanding among people, so that they understand the perspectives of others. Through a mutual dialogical learning process, this may lead to the broadening of the horizons of all involved, and may pave the way for collective action to jointly change and improve a local situation. User involvement therefore requires a multi-stakeholder dialogue to involve users and professionals to better understand each other's perspective, and to be able to learn with and from each other and improve practices. As an evaluator, one has the responsibility to organize support and facilitate this dialogue. As perspectives come together, this is often a difficult space with many moral dilemmas, and emotion work.
2. This epistemology values scientific knowledge, but it endows equal value to practical-professional knowledge developed by practitioners in their work and existential-experiential knowledge developed by clients and patients. It also appreciates artistic representations as a valid source of knowledge. Alie Weerman (2016, 2020) explained that experiential knowledge typically reveals the existential dimensions of life and issues that are related to human suffering, to pain, the experience of one's vulnerability, the loss of control and autonomy, and dependency. It also reveals the experiences of discrimination, stigmatization and marginalization in society. Because of its nature, this type of knowledge is much more fragile, fragmented and sometimes chaotic (Stuij et al., 2019). This type of knowledge is easily

silenced, as my personal story illustrated, and this may lead to a situation of 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). Therefore, in horizontal epistemology users are deliberately included as 'legitimate knowers'. Miranda Fricker (2007) has described this as a strategy towards 'epistemic justice': to actively include the voices of those whose issues are at stake, and who have formerly been wronged in their capacity of knowing (for example patients, women, people of colour, etc.), and whose voice did not count as relevant in a certain context.

3. In such an epistemology, we acknowledge that human beings (including researchers) interpret and construct knowledge, and that our own situation and perspective influence what we see/do not see and select. This epistemological notion implies that we constantly reflect and doubt what we know, and consider how power interferes in how we come to know the world. We have to ask ourselves and others whether we impose a certain reality more or less on others or if we provide a space for the untamed experiences of other people. In other words, our worldview is always situated and partial. The voices of users and the marginalized are important in the process of knowledge co-creation because their questions may point towards different phenomena and understandings of situations.
4. Another characteristic of horizontal epistemology is the personal involvement of the researchers, and a greater appreciation of personal motives and experiences as rich and helpful sources that lead to a deeper understanding of the lives of the people with whom we work. We have increasingly brought in our personal selves as 'agents of knowledge' beyond our distanced, academic, professional gaze, precisely because personal, embodied experiences, our own included, are important resources of knowledge. By doing so, we place ourselves under scrutiny as well, instead of presenting ourselves as the impartial, anonymous voice of knowledge (Baur, 2012; Bos, 2016; Woelders, 2019). This also means that we develop more horizontal and equal relationships with our co-researchers, and we all become involved in studying our lives (Abma et al., 2019a).
5. Horizontal epistemology includes a refocus, one that focuses less on methods and techniques and the collection and analyses of data, and more on the creation of a 'communicative space' wherein we can generate knowledge from studying our own lives together with others (Abma et al., 2019a). The concept of

communicative space has its roots in the work of Habermas (1987) who identified the ideal place for people to come together as a place of ‘... mutual recognition, reciprocal perspective taking, a shared willingness to consider one’s own conditions through the eyes of the stranger, and to learn from one another’ (p. 291). This type of communication does not seek harmony, instead it challenges the traditionally asymmetric relationship between those with lived experience and taught ‘experts’ shifting towards an inclusive approach where the focus is on learning together to create new ways of acting (Cook, 2020). Critical thinking, listening, questioning and dialogue are central, as well as self-reflection about one’s identity and positionality of power, such as by race/ethnicity, education, role and research knowledge. This requires openness, receptivity to otherness, sensibility and critical reflection upon the assumptions, limitations and blind spots of the participants in a dialogue and their own discourse. We are fully aware that such a communicative space is not a space where power, conflict, dissensus, interests and strategic action are not at stake; power always permeates our work because certain things cannot be said in certain discourses and therefore cannot find expression, or can only find expression in ways other than words, like in art. It is not only the power in the context but also our own power we need to be reflexive about in our work. And if we cannot escape from power we have to be conscious of the purposes we use it for, and how we can use it to realize the normative horizon of participatory research.

Good Participation Requires Ethics Work

Our work brought us to the notion that participation and participatory research entails ‘ethics work’ (Banks, 2016). I have described this as follows: ‘Ethics work’ entails the effort one puts into seeing ethically salient aspects of situations, developing oneself as a reflexive practitioner, paying attention to emotions, collaboratively working out the right course of action and reflecting in the company of critical friends. I have shown with my personal story that ‘ethics work’ is needed because otherwise the voice of users may get lost, leading to the silencing of knowledge. ‘Ethics work’ requires reflection on the academic and organizational context and accompanying rules and routines that may lead to the exclusion of voices. Is the researcher prepared to bend these rules in order to create a space for the voice and knowledge of users? Does one dare to renegotiate a contract with a commissioner when more time is needed for the involvement of users? Does one have the courage to stand up and take a position in favour of the inclusion of the users’ voices? This commitment to epistemic justice requires ‘ethics work’, which is intense, often exhausting and without easy answers. ‘Ethics work’ includes ‘identity’

and ‘emotion’ work according to Banks:

‘Identity work – working on one’s ethical self; creating an identity as an ethically good professional; negotiating professional identity; maintaining professional integrity.’ (Banks, 2016: 3)

‘Emotion work – being caring, compassionate and empathic; managing emotions; building trust; responding to emotions of others.’ (Banks, 2016: 3)

Identity work entails the personal and moral development of the participatory researcher. One of leading researchers in the case presented, Barbara Groot, reflects on the development of her identity as a participatory researcher in her PhD thesis. She reveals that learning to see ethically salient situations is not something one does on one’s own nor can it be learnt by the book. It was through practice, by working in the field with service-users, that she became aware of the moral complexities of participatory research, and it was in the company of befriended researchers that she became more sensitive to these issues:

‘At that time, ethics was, in my perception, an informed consent letter for participants, and a check of the Ethics Board Commission at the start. I was focused on learning about the methodological quality of PHR. Ethics was not in my vocabulary and scope those early days. However, in practice, I had a lot of questions. How do you deal with volunteers in the right way? ... What to do when a user leaves an urgent message on Friday evening? Who is responsible for the group dynamics in co-research teams?’ (Groot et al., 2020)

Identity work is related to the development of virtues like courage. Indeed sometimes one has to take a stance, like the Director of the Client Advocacy Organization, who asked about the perspective of clients in the Town Hall meeting. As researchers we also had to take a position in the process when service users and experts by experience felt that they were not being heard or when voices were silenced. The researcher’s position is crucial in determining the possibilities there are for experiential knowledge. If we had not acted when the experiential researchers in our team they felt excluded from the process, this would have had a large impact upon the collaboration and room for their voices. Participatory researchers determine the possibilities for open spaces in which various sorts of knowledge can emerge and coalesce. Often there are clear structures and frameworks within which one has to work as a researcher or professional. They can restrict the voices of patients and clients. Take, for instance, the deadlines set by commissioners and the request to share research findings through written reports. I have illustrated how the response

of our co-researchers confronted us with the power structures in the context, and our own power to dominate or to use our power for the value of social justice.

The case also illustrates that there is not always room for what users want to express. In the case, the co-researchers called for a safe space to express their inner feelings. Participatory researchers therefore bear the responsibility to create such a safe space. We also saw that language may not adequately express feelings; this is why we introduced images in the report. Moreover, users may not have the capacity to express themselves, like in the case one of the co-researchers who could not take part in the writing process, which excluded her from knowledge production. In all these instances, the participatory researchers had to deliberately create a situation wherein feelings and experiences could be expressed and shared. This meant that the researchers had to leave their comfort zone – their scientific distance and verbal weaponry – and respond to the context. We did so by working more intuitively. This changed the interaction. We learned we had to give up our control over the situation – and our privilege – to come to know and appreciate how to develop a relationship with more space for the co-researchers and users. This made us feel uneasy; were we still perceived to be academic researchers? Yet this rebalancing of power also created a situation for mutuality, where both were giving and receiving affectionate attention, and a feeling of mutual belonging and interconnectedness (Groot et al., 2019a).

We also learned how important emotions are, and redefined dialogue beyond the verbal and rational, where participants responded to each other, each other's position and each other's particularity – by means of their language, bodies, attitudes and/or emotions. Dialogue was re-enacted as a 'dia-logos' with an 'intercorporeal' and embodied character. Thus, when we want to understand someone else we must not only focus on words but must also pay attention to everything that happens in between. This allows us to understand, instead of objectifying and grasping, the complexity of another human being. Yet this requires something of the researcher, namely self-insight and reflection. The more complex and messy our situation, the more we need self-insight and dialogue to develop a moral basis in relationships with others. It goes without saying that this is challenging, but it also may bring ethical richness, fulfilment, meaning, motivation and the experience of togetherness.

So, participatory research is not a matter of following protocols and guidelines; it is much more a matter of opening up to and for another person, letting oneself be emotionally moved by the story of this person, and accepting the moral appeal that may flow from this relationship. This is certainly not easy in current organizations that focus on rational knowledge and control, and a professional, distanced

attitude. This requires emotion work.

Emotion work includes, for example, investing in building a solid research team with and without experiential knowledge and good collaborations by taking decisions together (Groot et al., 2019a). Emotion work was also part of preparing a dialogue meeting with all stakeholders, and responding to the call of experts by experience to be included in writing the report and to take their anger seriously when the commissioners requested an adjustment of the report because it was too critical in their eyes.

No wonder we sometimes felt exhausted. Much of the identity and emotion work relates to developing a horizontal relationship with the people we work with. It confronts us with questions like: Are we prepared to give up our privileged expert status? Are we willing to work with people who confront us with our moral responsibilities and our position in society – and privileges we often take for granted, like having a stable income and being able to do meaningful work, for instance? Are we willing to attend to the relationships and to develop a mutual intention to understand and respect each other? Are we willing to enter the difficult and ‘messy’ spaces, to stand up for an interest? All I can say is that these encounters really confront us with ourselves, they function as a mirror, and destabilize us. I have also felt how people appeal to us morally, like in my story, based on the expectations and relationships we built up over time. We cannot just deny this, but at the same have our own needs and desires and other obligations.

This emotion work, the handling of our own emotions and those of who we work with, refers to the ‘management’ of emotions (Hochschild, 1983). Banks (2016) places emphasis on empathy and attention from a care ethics perspective, but we also may have emotions like anger, sadness, jealousy and shame to manage. It can be hard to always be empathic and caring. We may not always be true to our inner feelings, and feel alienated. Users are not always nice to us, to each other and other stakeholders. They may carry a lot of pain and despair; professionals may also feel exploited and used by the system. In such circumstances it can be very hard to respect and understand each other. Dealing with the emotions of users and professionals who feel they are not acknowledged, who feel irrelevant, also confronts us with their suffering, the losses in their lives, the bereavement due to loss and sorrow.

Emotion work is grounded in the notion that good care requires embracing rather than ‘glossing over’ emotions and feelings. ‘Glossing over’ feelings implies a superficial engagement with the emotional complexities of caring and responsibility; what is required is a much deeper and emotionally challenging engagement that redefines our

relationships (Zembylas et al., 2014). Many of us have experienced feelings and emotions as intelligent phenomena that require thoughtful emotional work, which, in turn, helped us to understand what other people needed and to establish a relationship of trust (Baur, 2012; Bos, 2016; Visse, 2012; Woelders, 2019).

My concern about ethics work is part of a more general turn to ethics. Lately we have seen an increasing interest for ethics in academia and among policymakers to counter-balance managerialization and professionalization with a focus on the neutral, distanced professional, technical and instrumental knowledge. This has led to the development of a new (type of?) managerial ethics. Policymakers focus on standards and codes, manuals and protocols, as well as on skills training and conforming with rules. There is a concern that this leads to a ‘thinning’ of ethics to rules and procedures, ticking boxes and working by the book. New managerial ethics when taken too far may lead to unthinkingly following the rules, eroding the critical capacities of professionals required for making good decisions (Banks, 2016).

Yet we can also see an increasing interest in ‘everyday ethics’ which is grounded in the idea that ethics is embedded in professional and personal lives, that it extends rules, principles and rights, and includes care, emotions, responsibilities, moral character and the acknowledgment of the situation and context which cannot be predicted and ‘dealt with’ in advance. This more horizontal approach of morality is derived from ethics of care, virtue ethics, situational ethics and empirical ethics (Widdershoven, 2000). It challenges the idea that philosophers have a monopoly on ethics, and imports ideas from psychology, sociology and anthropology. I feel that this everyday ethical approach as well as care ethics, with an interest in the embedding of ethics in what we do, is much more in line with our work (Brannelly, 2018). This kind of ethics is embodied, acknowledging feelings and emotions. It ‘enriches’ ethics with context and concrete situations as well as with the broader political context. In that sense, everyday ethics reclaims ethics from neoliberal, rule-based approaches.

The Future: Good Company, Critical Friends and Participatory Reflection

I have shown that participatory research is morally complex and full of everyday ethical issues that require attention and ‘ethics work’ from the participatory researcher. This leads me to question how we can cultivate and prepare ourselves for the ‘ethics work’ that is part of participatory research. This includes questions like how does one develop moral sensitivity, develop courage, learn to bend and break rules, and stimulate personal and professional development of participatory researchers? I have learned that it is possible and fruitful

to encourage novice as well as more seasoned researchers to develop their moral compasses and sensitivities by working in groups, through role modelling, rehearsal, reflection and talking about urgent cases, by sharing moral distress and uncertainty, by starting to see that one can take some action. Researchers in my team have expressed the need for the good company of critical friends, and coalitions of solidarity in mixed groups with service users, community organizations, policymakers, professionals and academics. We have also learned that political action does not need to be large scale, that small wins are important, give us hope, and inspire us.

We have also learned that we need more acknowledgement of the personal factor in what we do, and how our understanding of our personal lives can help to gain a deeper understanding of the complexities of the lives of the people with whom we work. This is a delicate and challenging process, but also a very fulfilling experience because it makes our work much more meaningful, intense and more true to the ethical complexities of our inner and outer worlds. To develop as persons we need critical friends, a company of people who are sympathetic to our intentions and desires, who recognize our core values and principles, and who can raise tough and difficult questions. Such a company or community of practice is characterized by longstanding friendly relationships, and a safe environment. The Centre for Client Experiences and the International Collaboration of Participatory Health Research (ICPHR) have offered such space to my team and me, and helped us to face the difficult ethical questions that can be raised about our work. In the company of these friends, we can practise collaborative and participatory reflection and face the moral complexities of our practice and cultivate 'ethics work'.

An issue up for discussion is what this means for funding agencies and policymakers who want to promote good participatory action research and user involvement. First of all it is important for these stakeholders to show a genuine interest in the practice of participatory research and epistemic justice, and a willingness to develop that practice within organizations. Participatory research is complex and can only be learned in and through practise. So, funders and policymakers should create room for reflection and learning based on dialogue and deliberation among researchers and participating stakeholders. Secondly, they need to ask themselves critical questions like what does one want to achieve with participatory research? What are the reasons for the participation and involvement of users? Is there a willingness to share power equally with all the stakeholders, and accept findings and outcomes that may differ from initial ideas and plans? Thirdly, policymakers and funders need to evaluate how their organizations and systems interfere with the practice of participatory research. Is there a willingness to remain flexible and to renegotiate plans and timelines? Is 'messiness' accepted as part of the practice? Can we find

ways to assess the quality of the practice other than mere outcome measures like the number of publications?

Other issues include whether we should hold on to normative ideals if they are hard to realize in practice, and whether we should choose participatory research if it involves so much effort. Those who share a commitment to epistemic justice will argue that the voices and perspectives of all whose lives and work is at stake should be included in a study that investigates their experiences. Their inclusion also honours their fundamental human right to be acknowledged in their capacity as knowers of their worlds, and that all perspectives are needed to gain a full understanding of the studied phenomenon. Moreover, normative ideals function as a moral horizon; they are helpful not because they can be easily realized in practice but because they offer us a moral compass (Habermas, 1987).

Once we have committed ourselves to participatory research and underlying ideals we cannot just ignore the responsibility and ‘ethics work’ that comes with it. Yet there are sometimes good reasons not to choose participatory research. One should only choose this methodology if the goal is the heightening of mutual understanding among stakeholders and a change of practice. There are better, more suitable alternatives if the aim is description or explanation. Moreover, the necessary conditions for participatory research need to be in place for a project to be successful. Lack of resources, time, capabilities and political conflict may constitute contraindications (Abma et al., 2019a).

Finally, it is not clear whether this kind of work is feasible within the current academic setting. In general, participatory research is not (yet) well integrated in academia because most universities and disciplines are still grounded in a vertical epistemology in which the expert produces knowledge without the active involvement of stakeholders. The neoliberal culture and trends of universities may challenge this kind of work (Gill, 2016; Boden et al., 2015). Western universities are increasingly organized according to bureaucratic schemes of administration, commoditization of research and teaching, and command-and-control management. This has pushed universities away ‘from their potential to act as sources of community and citizen development and the promotion of a better and fairer society’ (Boden et al., 2015: 289). Hence the rise of participatory research often takes place outside universities. As is the case in many other countries, a growth in university-wide support structures for participatory researchers is still lacking in the Netherlands. Many participatory researchers work alone in their departments without much support from colleagues or the administration. I see a need for knowledge exchange among these scholars about the practice of participatory research and how to conduct it and collaborate with users in good,

ethically responsible ways. This does not mean that participatory research is only possible outside universities. I also think it is fruitful to search for connections and stay connected to university contexts to create openings within these contexts for horizontal epistemologies. My hope is that we will develop communities of practice, such as the Centre for Client Experiences and the ICPHR mentioned above, to help researchers and other stakeholders to develop the practice of participatory research and commitment to epistemic justice.

Literature

Abma, T. (2006). The practice and politics of responsive evaluation. *American Journal of Evaluation*, 27(1), 31-43.

Abma, T.A., & Widdershoven, G.A.M. (2014). Dialogical ethics and responsive evaluation as a framework for patient participation. *The American Journal of Bioethics*, 14(6), 27-29.

Abma, T.A., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J., & Wright, M. (2019a). *Participatory research for health and social well-being*. Switzerland: Springer Nature.

Abma, T., Groot, B., & Widdershoven, G. (2019b). The ethics of public and service user involvement in health research: The need for participatory reflection on everyday ethical issues. *The American Journal of Bioethics*, 19(8), 23-25,
DOI:10.1080/15265161.2019.1619869

Alvarez-Pereira, C. (2019). Emerging New Civilization Initiative (ENCI): Emergence from emergency. *Cadmus*, 1(4), 1-13.

Banks, S. (2016). Everyday ethics in professional life: Social work as ethics work. *Ethics and Social Welfare*, 10(1), 35-52.
DOI:10.1080/17496535.2015.1126623

Banks, S., & Brydon-Miller, M. (2019). *Ethics in participatory research for health and social well-being: Cases and commentaries*. Abingdon: Routledge.

Baur, V.E. (2012). *Participation & partnership: Developing the influence of older people in residential care homes*. Doctoral thesis, VU Amsterdam.

Boden, R., Greenwood, D.J., Hall, B., Levin, M., Marshall, J., & Wright, S. (2015). Action research in universities and higher education worldwide. In H. Bradbury (Ed.), *The Sage handbook of action research* (pp. 281-290). London: Sage.

- Bos, G. (2016). *Antwoorden op andersheid: Over ontmoetingen tussen mensen met en zonder verstandelijke beperking in omgekeerde-integratiesettingen*. Doctoral thesis, VU Amsterdam.
- Bradbury, H. (Ed.). (2015). *The Sage handbook of action research*. London: Sage.
- Brannelly, T. (2018). An ethics of care research manifesto. *International Journal of Care and Caring*, 2(3), 367-378.
- Cook, T. (2020). *Participatory research: Its meaning and messiness*. Keynote lecture, Responsive, Participatory Research: Past, Present and Future Perspectives. Vrije Universiteit, Auditorium, Amsterdam, 20 January 2020.
- De Wit, M. (2013). *Patient participation in rheumatology research: A four level responsive evaluation*. Doctoral thesis, VU Amsterdam.
- Domecq, J.P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., ... & Erwin, P. (2014). Patient engagement in research: A systematic review. *BMC health services research*, 14(1), 89.
- Fetterman, D., Rodriguez-Campos, L., Zukoski, A., & Contributors Collaborative. (2018). *Participatory, and empowerment evaluation: Stakeholder involvement approaches*. New York/London: The Guilford Press.
- Fricker, M. (2007). *Epistemic injustice: Power & the ethics of knowing*. New York: Oxford University Press.
- Gill, R. (2016). Breaking the silence: The hidden injuries of neo-liberal academia. *Feministische Studien*, 34(1), 39-55.
- Groot, B.C., Vink, M., Haveman, A., Huberts, M., Schout, G., & Abma, T.A. (2019a). Ethics of care in participatory health research: Mutual responsibility in collaboration with co-researchers. *Educational Action Research*, 27(2), 286-302, DOI:10.1080/09650792.2018.1450771
- Groot, B.C., Vink, M., Huberts, M., Schout, G., & Abma, T.A. (2019b). Pathways for improvement of care in psychiatric crisis: A plea for the co-creation with service users and ethics of care. *Archives of Psychology*, 3(3). Available at <https://archivesofpsychology.org/index.php/aop/article/view/99>
- Groot, B.C., Haveman, A., & Abma, T. (2020). Relational, ethically sound co-production in mental health care research: Epistemic injustice and the need for an ethics of care. *Critical Public Health*.

Habermas, J. (1987). *The theory of communicative action, Volume 2: Lifeworld and system: A critique of functionalist reason*. Cambridge: Polity Press.

Hochschild, A.R. (1983). *The managed heart: Commercialization of human feeling*. Berkeley: University of California Press.

International Collaboration for Participatory Health Research (ICPHR). (2013a). *What is Participatory Health Research?* Position Paper No. 1. Berlin: International Collaboration for Participatory Health Research.

International Collaboration for Participatory Health Research (ICPHR). (2013b). *Participatory Health Research: A guide to ethical principals and practice*. Position Paper No. 2. Berlin: International Collaboration for Participatory Health Research.

Kunneman, H. (2017). *Amor complexitatis: Bouwstenen voor een kritisch humanisme. Deel 2*. Amsterdam: SWP.

Kunneman, H. (2020). *Complexity and its relevance for knowledge production*. Keynote lecture, Responsive, Participatory Research: Past, Present and Future Perspectives. Vrije Universiteit, Amsterdam, 20 January 2020.

Nierse, C. (2019). *Collaborative user involvement in health research agenda setting*. Doctoral thesis, VU Amsterdam.

Schipper, K. (2012). *Patient participation & knowledge*. Doctoral thesis, VU Amsterdam.

Schön, D. (1983). *The reflective practitioner*. Aldershot: Ashgate Publishing.

Schwandt, T. (2020). *Responsive and post-normal evaluation*. Keynote lecture, Responsive, Participatory Research: Past, Present and Future Perspectives. Vrije Universiteit, Auditorium, Amsterdam, 20 Januari 2020.

Staniszewska, S., Brett, J., & Mockford, C. (2011). The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research. *International Journal of Technology Assessment in Health Care*, 27(4), 391-399. doi:10.1017/S0266462311000481

Stuij, M., Elling, A., Tramper, A., & Abma, T. (2019). Developing a relational narrative about diabetes: Towards a polyphonic story. In P. Bray (Ed.), *Voices of illness: Negotiating meaning and identity* (pp.

248-268). Leiden/Boston: Brill/Rodopi.

Tronto, J.C. (1993). *Moral boundaries: A political argument for an ethic of care*. Hove: Psychology Press.

Tronto, J.C. (2013). *Caring democracy: Markets, equality, and justice*. New York: New York University Press.

Van Lieshout, F., Jacobs, G., & Cardiff, S. (2017). *Actieonderzoek: Principes voor verandering in zorg en welzijn*. Assen: Koninklijke Van Gorcum.

Visse, M. (2012). *Openings for humanization in modern health care practices*. Doctoral thesis, VU Amsterdam.

Visse, M., & Abma, T. (Eds). (2019). *Evaluation for a caring society*. Charlotte, NC: IAP Publishers.

Voronka, J. (2016). The politics of 'people with lived experience' experiential authority and the risks of strategic essentialism. *Philosophy, Psychiatry & Psychology*, 23(3/4), 189-201.
DOI:10.1353/ppp.2016.0017

Weerman, A. (2016). *Ervaringsdeskundige zorg- en dienstverleners*. Doctoral thesis, VU Amsterdam. Eburon.

Weerman, A. (2020). *Follow the dog: Experience as a third source of knowledge*. Keynote lecture, Responsive, Participatory Research: Past, Present and Future Perspectives. Vrije Universiteit, Auditorium, Amsterdam, 20 Januari 2020.

Widdershoven, G.A.M. (2000). *Ethiek in de kliniek*. Amsterdam: Boom.

Woelders, S. (2019). *Power-full patient participation: Opening spaces for silenced knowledge*. Doctoral thesis, VU Amsterdam.

Zembylas, M., Bozalek, V., & Shefer, T. (2014). Tronto's notion of privileged irresponsibility and the reconceptualisation of care: Implications for critical pedagogies of emotion in higher education. *Gender and Education*, 26(3), 200-214.
DOI:10.1080/09540253.2014.901718

This article is based on my keynote lecture 'Doing Participation. Lessons Learned and Perspectives' presented at the symposium entitled Responsive, Participatory Research: Past, Present and

Future Perspectives. Vrije Universiteit, Auditorium, Amsterdam, 20 January 2020. I would like to thank Tina Cook, Harry Kunneman, Thomas Schwandt and Alie Weerman for their presence and keynote lectures given on 20 January 2020, my research team and all co-researchers for their insights and experiences, for being willing to explore and experiment, for staying committed, for the mutual learning and helping me to build a body of work I believe in.