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Published online: 14 May 2023.

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Researching with Care – Participatory Health Research with Afghan Women Refugees in Germany During the Covid-19 Pandemic: A Case with Commentaries

Naseem S. Tayebi [iD][a], Marilena von Köppen [iD][b,c], Petra Plunger [iD][d], Susanne Börner [iD][e] and Sarah Banks [iD][f]

[a]Institute for Medical Information Processing, Biometry and Epidemiology (IBE), Faculty of Medicine, LMU Munich, Munich, Germany; [b]Institute of Social Medicine & Health Systems Research, Otto-von-Guericke University Magdeburg, Magdeburg, Germany; [c]Department of Nursing and Health, Fulda University of Applied Sciences, Fulda, Germany; [d]Austrian National Public Health Institute (Gesundheit Österreich GmbH), Vienna, Austria; [e]School of Geography, Earth and Environmental Sciences, University of Birmingham, Birmingham, UK; [f]Department of Sociology, Durham University, Durham, UK

ABSTRACT

This article comprises a short case exemplifying ethical challenges arising for a participatory researcher working with Afghan women refugees during the Covid-19 pandemic in Germany. The researcher is an Iranian-German woman, qualified as a midwife, undertaking doctoral research on refugees' access to reproductive health care. Disclosures about some women's experience of domestic violence are made, which raise ethical issues for the researcher relating to personal-professional boundaries, roles and responsibilities. Two commentaries are given on this case from participatory researchers based in Germany, UK and Austria. Both commentaries highlight the relevance of the ethics of care for participatory research and for this research in particular, which entails very close relationships between the doctoral researcher and the refugee women with whom she is researching. The first commentary analyses the research process in terms of Tronto's five phases of care, while the second illustrates the importance of caring institutions in supporting researchers working on sensitive topics.

Introduction

Sarah Banks

This article has been created by members of the Ethics Working Group of the International Collaboration for Participatory Health Research. It comprises a case study of a researcher's experience of an ethically challenging situation, followed by two reflective commentaries from researchers with an interest in the topic, but no prior knowledge of, or involvement

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in, the case. The case is an account of a participatory research project with refugee women, highlighting some of the ethical challenges raised in relation to researcher positionality. Participatory research involves people with experience of the topic of study playing a role in the design and implementation of the research, or at least engaging in participatory methods to co-create their own stories and accounts (as in the case presented here). Ethical issues relating to power, positionality and privacy are common in participatory research (Banks and Brydon-Miller 2019; ICPHR 2022). This case and the accompanying commentaries illustrate the care needed when juggling different roles as researcher, friend and advocate, for example.

The case: participatory research with Afghan women refugees in Germany during the Covid-19 pandemic

Naseem S. Tayebi

Background

This case is based on my PhD participatory health research project, aimed at investigating Afghan women refugees' challenges and experiences in accessing reproductive healthcare after arriving in Germany. The study provided an opportunity for participants to develop their self-help competencies individually and within their communities. The community partners in this study were women refugees aged 22–40 with from zero to six children, who had lived in the suburbs of Munich since 2015. Some had developed close friendships through living in refugee camps together for several years. I already knew several participants since I had worked as a volunteer accompanying them on visits to health care centres and meetings with the authorities since 2015. The project consisted of eight participatory meetings with nine women refugees between December 2019 and June 2020. Photovoice was also used in these meetings in order to give the participants a further possibility, in addition to oral and written expression, to present themselves and explain experiences with pictures and images. Photovoice involves people taking photos of significant feaures of their lives, often writing short commentaries on the pictures (Brandt et al. 2017; Wang 1999).

Before the Covid-19 pandemic 'lockdown', I conducted four participatory meetings with six community partners, which gave them the opportunity to share their experiences and exchange their stories. The restrictions from March 2020 made it difficult to hold meetings. Despite these obstacles, several factors including the trust and partnership built in the group, the willingness of the mothers to help progress the project, and the inclination for in-person (not virtual) meetings made it possible to organize gatherings in keeping with hygiene regulations. Hence, meetings were held in smaller groups consisting of the doctoral researcher and two or three women refugees as co-researchers.

The small participatory meetings were rich, with a remarkable atmosphere in which refugee women could share their stories and explore their strengths. The women described their relationship as a 'sisterhood' (خواهرانه). They had formed bonds during the long journey to Germany, on their arrival and while living in temporary camps together. Often I engaged in self-reflection on my position and power during the research and on the ethical concerns. Being witness to the women's challenges and having shared

the experience of being an Iranian immigrant to Germany, I felt I was an insider in this study in addition to being an academic outsider. I was fortunate to be able to communicate with the women in their mother tongue without the intervention of an interpreter. Care was taken that they understood there was no obligation to participate and they could withdraw at any time if they felt uncomfortable during participatory meetings.

The opportunity to be present in these women's private lives and observe their personal dilemmas was very precious to me and was kept separate from the research, as private knowledge and memories, to honour their trust. The observations are in my field notes, as they were closely related to my research. But the women's personal challenges are excluded from my quotations. Ethically my position as a friend took precedence over my position as a researcher.

Ethical dilemmas of a facilitator

During the meetings I played the role of facilitator, which superseded my role as an advocate or health professional. This was sometimes challenging, and I was conscientious in enabling the voice of mothers to be heard without causing them harm in their community. If while explaining her stories one of the women was blamed by the others, I intervened immediately in the discussion and diverted the theme. My aim was for none of them to feel ashamed or lose their position in the community because of their testimony. As a precaution I encouraged them to contact me if they had any issues or inquiries related to the research and meetings. Participants trusted me and spoke freely during meetings. I repeatedly informed them of the importance that confidentiality holds in my project and allayed any concerns that their statements might be leaked to friends and peers, since the refugee community is tightly knit.

In one instance, a sensitive topic raised by some women was domestic violence. When a participant raised this issue, others found the courage to relate their experiences as well. In that moment my position as a facilitator was tricky; I was not adequately prepared to respond properly. I listened without intervening in the discussion. However, as an advocate, I felt obliged to respond to their questions. I supported these women and reminded them of their strength and autonomy. In retrospect I see the necessity to be better prepared for sensitive issues to arise. Nevertheless, most of the women were thankful for these meetings and for me listening to their voices in their own language. This had not happened before. Eventually they found their strength and exposed their experiences of severe domestic violence, many of which were amplified during the pandemic lockdowns, to social workers and German volunteers, who notified the responsible authority. Furthermore, I provided a list of organizations that support refugees and specialize in mental health, and suggested the women could contact me whenever needed.

Being both researcher and health professional

One of my ethical concerns during the lockdown was to maintain contact with participants, especially those with health issues. Six of the women (two of whom were pregnant) became infected with Covid-19 and were hospitalized and quarantined. I received many distressed calls from the mothers. The main challenge that refugees face is communication barriers when accessing health and maternity care services. These difficulties escalated during the lockdown when companions were not allowed to support them at their hospital visits. For this reason, I actively supported them by answering questions and

translating via telephone, often when they visited health care centres. As a midwife, offering support in these circumstances was fundamental.

In conclusion, the pandemic raised new ethical issues, and through being flexible, successful small participatory meetings were held. Solidarity generated between the women was a key factor in maintaining their health and giving a voice to their stories.

Commentary 1

Marilena von Köppen

The case is a good example of the multiple ethical challenges academic researchers face when conducting participatory research with people regarded as marginalized and 'vulnerable'. Through the author's personal and reflexive account, we get the picture of a deeply caring researcher, in contrast to the ideal of an emotionally and socially detached researcher striving for objectivity, as is often still advocated in positivist-influenced methodologies.

The need to integrate care into the collaborative research process and expand participatory methodology and research ethics from the perspective of doing research with care has been increasingly pointed out (Brannelly and Barnes 2022; Groot et al. 2018). The ethics of care, which is based on a relational ontology and for which interdependence and vulnerability form the core of human existence, offers starting points. The definition of care developed by Fisher and Tronto (Tronto 2009, 2013), which comprises a total of five phases of the caring process and links them to elements of care, can be used as a reflective framework to illuminate the ethical dilemmas in research practice.

Caring about, the first phase, requires that researchers perceive the needs of those involved in the research. This requires *attentiveness*. Through her own history as a migrant and her work as a volunteer, the author shares a common space of experience with the women. This helps her to recognize the special concerns and problems (e.g. language barriers, difficulties with access to the health care system). However, the needs of the different research participants are not necessarily aligned. As a PhD student, the author has certain objectives regarding completing the research and gaining a qualification, while for the women, needs for concrete help may be in the foreground. Caring about, therefore, refers to the need for all participants to listen carefully to each other and agree on research goals and procedures in a deliberative 'care-full' way.

Taking care of is the next phase and means taking *responsibility* for the identified needs and deciding how to deal with them. Given the vulnerability of the participants, this is a major challenge for the author. Thus, she points out to the women the risks and dangers that can be associated with participation, for example, if contents of conversations leak out. She decides not to publish certain personal information and experiences that the women share with her. This makes it clear that the author is not only committed to her research work, but also feels a responsibility towards the women. However, in doing so, there is also a risk of being over-protective in silencing the women's testimony and thereby contributing to epistemic injustice. In addition, the call to take on responsibility can also lead to the responsible person being overburdened. A PhD student's options for action and intervention are limited when she learns of specific incidents of domestic

violence. Taking responsibility therefore also means recognizing limitations to support and advocacy and addressing the issues together with others.

The third phase involves actual *care-giving*, which aims to meet the identified needs. It presupposes that this is done with *competence*. For researchers, this means they must know what they are doing in terms of methodology and research ethics. For early career researchers in particular, this requirement is demanding. The author also points out that facilitation is a particularly important task in participatory research. Facilitation skills are not usually part of academic training and include advanced knowledge in initiating meaningful dialogue to allow for co-production of knowledge. Furthermore, not only were the author's academic skills important, but also her professional experience as a midwife and health care expert. This shows that researchers need to bring their whole personality to the research process.

Part of care-giving is to consider *care-receiving*. This is about the *responsiveness* of the care-recipients; only from their point of view can it be judged whether needs are being met. This also means being alert to possible abuses of power in research relationships. The openness of the women shows that they trust the researcher and each other. Maintaining this, however, requires an ongoing effort. The author describes situations in which participants were criticized or even shamed by others and in which she had to intervene. This requires constant self-reflection and joint reflection with co-researchers.

The final phase of care is *caring with*. It means the collective pursuit of justice, equality and freedom and requires the building of relationships of *solidarity*. Participatory projects, which in addition to gaining knowledge always seek social change for those involved, are particularly committed to this goal. The author describes that it is possible for women to discuss their experiences with domestic violence collectively with social workers and thus to represent their needs. However, such solidarity is often precarious and can easily dissolve after the end of a research project. It is therefore also the responsibility of the researchers to reflect on the concrete impact of the research and to create opportunities for solidary relationships to continue.

Commentary 2

Petra Plunger and Susanne Börner

The first point that is striking is the complexity of the roles and how these are interwoven with the researcher's positionality: the author is at the same time a researcher and facilitator, a friend as well as a trained health professional. She describes how these identities play a fundamental role in her research and support her interaction with the group of refugee women. An issue that comes to mind is the challenge of insider-outsider relations during the research process and the blurring of boundaries, where it is not always clear where the 'field' in fieldwork ends and the role of a friend begins (Hyndman 2001). While the author shares certain attributes with her participants (e.g. language) and is considered as a 'friend' ('insider'), she nevertheless still remains an 'outsider' to the 'sisterhood' of the women due to her role as a PhD researcher.

It is furthermore remarkable how the writer is concerned about caring for the women in her research. This raises the question of how to take good care of all those involved in the research process, and how to be taken care of as a researcher. Groot et al. (2018) base

their ethical case analysis and reflection on participatory health research on Tronto's 'second-generation ethics of care' to make the power relations in care relationships visible. This raises two central questions for researchers: how can we raise awareness of the fact that we all need care? And (how) do we feel safe to receive care from others?

We argue that, especially in sensitive research contexts (as in this case where issues such as domestic violence were raised), the focus should be on creating caring institutions (Tronto 2010). The author's identity as a PhD student in a university research context and the institutional context in which she is embedded are however only mentioned in passing. We argue that, here, principles of care ethics can help integrate a truly caring approach from an organizational perspective. Following Tronto's (2010) approach, we need to ask: What is (and should be) the role of supervisors and the university as an organization when reflecting on care in a specific participatory research context? This includes creating institutional support systems to make research environments psychologically safe to prevent, address and overcome researcher trauma (San Roman Pineda et al. 2022) as well as making the research process safe for all those involved. In relation to this case, this includes providing a supportive environment for dealing with 'researcher guilt' when the author felt that she could have been better prepared or given better support to the participants.

A final reflection relates to the confidentiality of data shared in a group (online or in person). Consideration is needed not only of the extent to which the confidentiality is being upheld by the other participants, but also of *what* is being shared with the group in the first place (Mavhandu-Mudzusi et al. 2022).

Acknowledgements

Disclosure statement

Notes on contributors

Naseem S. Tayebi is a public health doctoral student in the IBE institute, Medical Faculty of Ludwig-Maximilians-University, Munich. She is Iranian-German, and a public health and midwife specialist in qualitative and participatory health research in reproductive and maternal health with migrants and refugees.

Marilena von Köppen is research assistant at the Institute of Social Medicine & Health Systems Research, Otto-von-Guericke University Magdeburg, Germany and PhD candidate in the Department of Nursing and Health, Fulda University of Applied Sciences, Germany. She has a particular interest in ethics in participatory research, ethics of care and participatory research with older people.

Petra Plunger is a senior health expert at the Austrian National Public Health Institute (Gesundheit Österreich GmbH). She has a particular interest in health promotion and caring communities, ageing, dementia and participatory health research and ethics.

Susanne Börner was a Marie Sklodowska-Curie Fellow until February 2023, and is now Assistant Professor in the School of Geography, Earth and Environmental Sciences, University of Birmingham. She has a particular interest in participatory research with youth on urban wellbeing and youth everyday agency in contexts of resource insecurity and disaster risk.

Sarah Banks is Professor in the Department of Sociology and co-founder of the Centre for Social Justice and Community Action, Durham University, UK. She coordinates the Ethics Working Group of the International Collaboration for Participatory Health Research and has a particular interest in ethics in participatory research.

ORCID

Naseem S. Tayebi 🔴 http://orcid.org/0000-0003-0320-0385
Marilena von Köppen 🔴 http://orcid.org/0000-0003-4606-4803
Petra Plunger 🔴 http://orcid.org/0000-0001-6297-372X
Susanne Börner 🔴 http://orcid.org/0000-0002-0651-565X
Sarah Banks 🔴 http://orcid.org/0000-0002-2529-6413

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