COLLABORATIONS
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The Necessity of Unsettling Encounters in Collaborative Research – Reflections of Two Researchers without Experiential Expertise

REFLECTIONS ON EXPERIENTAL LEARNING PORTAL (STUDENT PORTAL)

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ABSTRACT

Background: Maintaining collaborative research relations is challenging, as shown by a range of personal accounts of researchers with experiential expertise, emerging from reflected lived experiences within medical or social care institutions.

Objective: In contrast, there is a shortage of narratives of researchers *without* experiential expertise, rendering their specific perspectives largely unaccounted for – a gap that is addressed in this paper.

Methods: The interpretative method of "interactive interviewing" is used to systematically reflect on how two researchers without experiential expertise perceived personal and emotional unsettlement in collaborative projects in the fields of Mental Health (MH) and Intellectual and Developmental Disability (IDD).

Results: Four cases are presented to illustrate and advocate the value of *unsettling encounters* in collaborative research. Underlying is the ethical and methodological position that collaborative research is primarily characterized by its potential to unsettle the relations between the people and parties involved. This position derives from the critical autobiography of the disability studies scholar Kathryn Church, and contrasts to the widely held assumption that collaborative research is largely characterized by a set of distinct methods or techniques.

Discussion: Some of the epistemic and methodological gains and challenges of approaching collaborative research as a means to facilitate and reflect on *unsettling encounters* are presented and discussed in relation to overarching theoretical and normative-ethical arguments.

Community Contribution: This paper purposefully lacks any form of involvement, explicitly focussing on the perspectives and experiences of researchers without experiential expertise in the context of collaborative research relationships.

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INTRODUCTION

In international research policies, there is increasing emphasis on the need for health service users to become active contributors within processes of academic knowledge production (Barnes, 1996; 2003; Nierse & Abma, 2011; Woelders, 2020; Wright & Kongats, 2019). In both research fields of mental health (MH) and intellectual and developmental disability (IDD), collaborative and participatory approaches have gained importance, whereas persons with experiential expertise, emerging from reflected lived experiences within medical or social care institutions (see below for definition), collaborate with or are part of multivocal academic research teams (Bigby et al., 2014; Frankena et al., 2019; Gilbert, 2004; Gillard et al., 2013; Nind, 2014; Rose, 2018). Their specific experiences, competencies, and perspectives are valuable sources of knowledge resulting into distinct benefits for research outcomes and practices (Frankena et al., 2015; Gillard et al., 2010). These benefits are shown to increase with the grade of involvement (Nierse & Abma, 2011), leading to the widely advocated claim that service users should have decision making power in all stages of the research process (Lambert & Carr, 2018; Nind, 2014; Sweeney & Morgan, 2009).

Maintaining collaborative research relations is challenging, as their partners usually vary considerably in terms of experiences, resources, knowledge, perspectives, privileges, power and positions (Embregts et al., 2018; Nind, 2017; Russo & Beresford, 2014; Woelders, 2020). Maybe this is why a slowly growing number of rather personal, highly interesting accounts on challenging collaborative research relations emerged during the past decade (Bos & Kal, 2016; Broznan, 2019; Carr, 2019; King & Gillard, 2019; Nind, 2017; Sandvoort, 2017; Sergeant & Sandvoort, 2019; Van der Lans, 2019), stemming from various disciplinary fields, and at times using grey literature as publication formats. In these accounts a variety of strenuous and painful experiences with collaboration and participation are described into detail, for instance resulting from the maintenance or reinforcement of professional power and roles (Davidow, 2020; Wildhood, 2019). Other authors mention the enduring stigmatizing of researchers with experiential expertise (Peels, 2019; Voronka, 2016), leading to feelings of devaluation as well as the disintegration of research perspectives (Jones & Cutler, 2018; Peels, 2019). In other cases, collaborative research has been enacted in rather technical, co-optative or objectifying ways, leading for instance to conflicts of authorship or to the appropriation of critical positions (Rose, 2017; Woelders et al., 2015).

Notably, most of these accounts, in both research fields of MH and IDD, primarily reflect on the experiences of researchers with experiential expertise, as they tend to be less positioned to circumvent the emotional labour linked to collaborative research (Jones & Cutler, 2018). In contrast, there is a shortage of accounts from researchers without experiential expertise, maybe due to the fact that they usually are in a professionally dominant (and personally safe) position which allows them to ask questions to, shape narratives for, or mobilize knowledge of, others – instead of being required to reflect on their own personal challenges and gains in collaborative research. This research gap is addressed in this paper, by presenting four cases from two researchers without experiential expertise who reflect on some unsettling yet productive personal experiences in collaborative research projects in the fields of MH and IDD. Underlying – and contrasting the widely held assumption that collaborative research is largely characterized by a set of specific methods or techniques (BMBF, 2016; Frankena, 2019; Maccarthy et al., 2019; MHRN, 2013; Pharos, 2020) – is our shared ethical and methodological position that this kind of research is primarily determined by its potential to (temporarily) unsettle the relations between the people and parties involved. The latter notion is further defined in the discussion and derives from the outstanding critical autobiography of disability studies scholar Kathryn Church (1995), in which she defines participation as something that "isn't (just) a new program technique or an intellectual exercise [but] an unsettling relation [that] will engage people emotionally and personally" (p. 74).

Accordingly, over the years, we both experienced that working collaboratively not only requires the application of specific techniques or methods but primarily a high degree of reflexivity, endurance, receptiveness towards criticism, and acceptance of personal and emotional turmoil. Even more, encounters which unsettle the researcher without experiential expertise appeared to be epistemically and methodologically essential to proceed with and advance our collaborative projects. To elaborate on this claim, this paper follows two research questions:

1. What do unsettling encounters in collaborative research mean for us; i.e. two researchers without experiential expertise?
2. What is the epistemic and methodological value of such an approach towards collaborative research?

The first research question is taken up in the results section, via four cases about some of the struggles and gains we experienced in collaborative research projects. The second research question will be attended to in the results section's comments as well as in the discussion, transcending our personal experiences by referring to overarching methodological, theoretical, and normative-ethical arguments in favour of facilitating and reflecting on unsettling encounters in collaborative research.

METHODOLOGICAL APPROACH

USE OF TERMINOLOGY

There is a broad discussion in both research fields of MH and IDD on when and why to use the terms "collaboration" (Stuhlfauth et al., 2019; von Peter, 2017), "coproduction" (King & Gillard, 2019; Lambert & Carr, 2018), "participation" (Gillard et al., 2013; ICPHR, 2013), "involvement" (Green, 2016; NIHR, 2021), "inclusive research" (Frankena et al., 2019; Nind, 2014), etc. We use *collaboration* to designate an epistemic partnership that neither necessarily starts from a shared (research) question nor aims at realizing a common political goal or shared results, but rather engages in common, systematic, and reflective efforts to expand forms of knowledge and practices of the researchers involved.

We preferred the designation "researcher with experiential expertise" to others, such as "service user" (Rose, 2017), "consumer" (Chamberlin, 2005), or "practice partner" (Lutz et al., 2020), to underline the expert position of the people with whom we are working (Boevink, 2017). This expertise mostly emerges from collective and systematic processes of reflecting on personal, lived experiences of spending time within the structures, logic, and routines of a medical, social or care institution – including related experiences of inequality, inferiority, powerlessness, exclusion, stigmatization (Boevink, 2017). Accordingly, and to reverse usual terminological hierarchies, we used "researcher without experiential expertise" as its counterpart, instead of notions like "academic partner," "scientific partner," "professional researcher," etc.

We use these terms despite of the fact that they are binary and therefore unjustly reduce the complexity of possibly – and as we think, widely existing – intersecting identities, also in the academic fields of MH and IDD. If anything, this article intends to further deconstruct this artificial and rudimentary distinction between "people with and without experiential expertise" – but we need to start from this dichotomy to reach this purpose. After all, as mentioned before, differences in experiences, resources, knowledge, perspectives, privileges, power, and positions are indisputably at stake between "researchers with and without experiential expertise," at least in our research fields. Using a binary terminology should help us do justice to these and other differences, while certainly carrying the risk of naturalizing them.

INTERACTIVE INTERVIEWING

In our search for answers to the research questions, the two of us engaged in a process of *interactive interviewing*, an interpretative method for getting an in-depth understanding of another person's experiences with emotionally charged and sensitive topics (Adams, 2008; Ellis, 2004; Tillmann-Healy & Kiesinger, 2001). Those participating in interactive interviews act both as researchers and research participants, bringing narratives in and helping to construct new ones. Thus, we engaged in a joint process of interweaving personal narratives with systematic reflections, resulting in a deepened personal and mutual understanding of how and why we were emotionally touched and disturbed by encounters with our research partners with experiential expertise, and in which ways these experiences shaped our epistemic and methodological approach.

Throughout this process, we embraced theoretical and methodological insights from social constructionist epistemology (Gergen, 2012), responsive phenomenology (Waldenfels, 2010; Waldenfels, 2011), critical ethnography (Madison, 2005) and friendship as method (Tillmann-Healy, 2003), which helped us to carve out our notion of *unsettling encounters*, and how the acknowledging of and reflecting on previous personal and emotional experiences may both epistemically and methodologically influence and advance collaborative research. Most importantly, the aforementioned account of Church (1995) was the main theoretical inspiration for this paper. Having worked for many years as a disability studies scholar, she writes very personally and reflexively about her collaborative relationships. Her critical biography, as other of her contributions (e.g., Church, 2008), starts with herself as a person. Stressing the importance of the researcher's positionality for undertaking (collaborative) research, Church provided the basis for our main argument – that (recognizing and reflecting on) feelings of unease, confusion, and discomfort during collaborative research may result into a variety of epistemological and methodological gains.

THE INTERVIEWING PROCESS

We started our process by exchanging a few personal narratives and thoughts on personal struggles and gains in collaborative research at a conference of *the International Collaboration for Participatory Health Research* (ICPHR) in Malmö, Sweden in 2016. Despite our working in different national, institutional, and disciplinary contexts, these appeared to be comparable in many ways. Hence, we decided to further inquire questions such as: What do we, as researchers without experiential expertise, gain by engaging in collaborative research (beside an academic career)? What are we feeling, doing, and thinking when collaborating? What does it mean for us to be involved in collaboration? And how do these questions relate to contemporary scholarship on collaborative research and our positions within and outside of academia?

Over the course of two years, we took these and other questions up during three, six-hour face-to-face interview sessions in Bochum, Germany, as well as in multiple telephone conversations. In between, we exchanged files that contained extensive notes and memos, resulting from our exchange, and further inquiring, elaborating, and commenting on them. Thereby, we carved out a collection of about 15–20 typical situations that had

happened to us during our collaborative projects, serving as an empirical basis for our discussion and reflections. While interacting, step by step, this collection narrowed down to the four cases below that seemed to best both illustrate and condensate our arguments. Taking these cases as a starting point, we jointly developed our article, by taking turns in writing it, by this means further deepening our reflections and mutual understanding.

Thus, instead of using a formalized way of collecting and analysing our experiences, we inductively and iteratively exchanged and reflected upon situations that happened in the context of our collaborative research projects. These reflections drew on our exchange, but also, of course, on previous thoughts, feelings, and interactions that happened in the context of the concerned projects (e.g. supervisory sessions or mediated group reflections), as well as our personal ways of engaging with the related subjects (e.g. processes of interviewing, training, coaching and therapy). Therefore, the insights given below partly emerged during the collaborative projects we refer to, and partly in a retrospective and co-constructive way. The notion of *unsettling encounters* as a central image for our manuscript was chosen in the second half of our interaction and heavily thought through until the end.

CONTEXT AND AUTHORSHIP

Collaborative research cannot be understood apart from the field in which it happens. Thus, our experiences and reflections may not suit other research fields but are highly specific to both our research contexts and us as persons. We decided to write jointly on the distinct experiences within our two different albeit interconnected fields (IDD and MH) for two reasons. First, collaborative research is currently heavily promoted in both fields, partly fuelled by their joint search for new forms of support. Second, and more importantly, both fields are united by their ongoing challenges caused by structural power asymmetries, relational inequalities, and forms of oppression. As much as collaborative research in both fields can neither be realized nor apprehended without taking these complex themes into account, the relations and research partners in both fields also considerably differ, as our four cases will illustrate.

Further, during our interactive interviews, we repeatedly reflected critically on our writing in favour of unsettling encounters without involving research partners with experiential expertise. Yet, this involvement would have given different answers to our questions – certainly equably valid, but different in their perspectives. Therefore, as much as our experiences relate to concrete situations, naturally also involving other people and perceptions, we decided to concentrate on our own perspectives, i.e. of two persons in the role of researchers without experiential expertise. Instead of reading the following as a detached description of what happened in the context of our collaborative research projects, it should be understood as a perspectivist account on how we felt and thought during them.

RESULTS

Our interactive interviewing process resulted in presenting four cases to illustrate what we mean by unsettling encounters in the context of collaborative research. The cases recapitulate some of our most intense, upsetting experiences within collaborative work. Instead of aiming at exhaustively covering all potentially relevant aspects of collaborative research partnerships, they intend to exemplify how engaging in this kind of research in the fields of MH and IDD may thoroughly invite personal and emotional engagement of researchers without experiential expertise – a phenomenon hitherto hardly discussed within research literature. In addition, the four cases seek to illustrate how these experiences of unsettlement may be of epistemic and methodological value in the context of collaborative research, beyond their personal gains for the researcher involved. Our focus on the struggles and gains connected to the rather challenging experience of personal and emotional involvement as academic researcher is deliberate and descends from our notion of *unsettlement* that will be further elaborated upon in the discussion.

CASE 1 (SEBASTIAN): FEELINGS OF GUILT IN, AND IMPLICATIONS OF, STRUCTURAL PSYCHIATRIC OPPRESSION

This first case stems from a collaborative working group that realised a participatory process evaluation within the larger context of a randomized, controlled trial, investigating new, more flexible, and continuous forms of psychiatric treatment in Germany. Our team was staffed by researchers with and without experiential expertise in an attempt to better align the research outcomes to the experiences, needs and values of service users. As a team, we established various techniques to systematically assess our collaboration, among others a supervision that took place three times a year by two persons with experiential expertise.

In one of these supervisory sessions, we reflected on our motivations for engaging in collaborative research. During this discussion, my own, still ambivalent drive between either working towards reforming or fighting against the current psychiatric system became a topic, even though I work within it myself. Talking through these contrary positions, questions arose on how much psychiatrists must be made responsible for the malice of psychiatric practices, such as coercion, isolation, and other types of violence. Analogies were drawn between collective forms of guilt of Nazi Germany and

those within psychiatry, leading to an intense and controversy debate of all of us involved.

This debate was highly unsettling to me, as it occurred during a period that gradually revealed how much of my family background played a role for me both engaging in collaborative research and fighting for more ethical psychiatric practices. Coming from a family that, on both sides, had been heavily involved in the viciousness of the NS regime, this debate added to further understand my feelings of obligation to do better by working together with and aiming at creating change for people whose lives are less privileged than mine.

Analogies between collective forms of guilt in Nazi Germany and the psychiatric institution are still highly unsettling to me (e.g., Chapman, 2014). Connecting these analogies to my family background and intentions for engaging in collaborative research is even more disturbing. At the same time, these analogies were of high epistemic value, both for me and my research partners, clarifying my motivations as a researcher: I understood that my motives for engaging in collaborative research had been blurred by my attempt to recuperate my family and re-install social justice – do I engage for my own sake, for the sake of the people I work with, for the sake of my family or for the sake of all?

Having understood this, my intentions became clearer to both myself and my colleagues to an extent that they have less been questioned again, both within the described group or other projects, facilitating our continuing proceedings. Earlier, I had been frequently asked by experiential experts about my intentions to engage in participatory and/or research that critically deals with the psychiatric institutions. My previous responses, such as "I want to contribute to social justice" or "I want to improve the user's situation," had proved not to be satisfactory, maybe as they rather technically dealt with my personal motivations. Digging into my family history and concretely connecting the findings with my research identity apparently had provided me and my surrounding with a more extensive and emotionally tangible explanation, making further inquiries less necessary.

Being open to personal reflections and disclosures may be necessary in every research project. Yet, it is pivotal to research partnerships that are usually characterized by unequal distributions of power, resources, and knowledge, causing different kinds of vulnerabilities and agenda among the persons involved. In this context, the willingness to become unsettled may not only facilitate research proceedings by levelling interpersonal disagreement or misconstruing but also improve the research outcomes at stake. At the same time, this willingness demands a lot from the involved researchers without experiential expertise – leaving aside the enormous emotional labour of the researchers with experiential expertise (Jones & Cutler, 2018). It may evoke feelings of guilt, shame, or hurtful experiences and emotions and it may involve, as in this case, discoveries of previously unknown facts. Finally, it deserves time and energy – to create space for deep engagement and reflexivity, and for coping with their consequences.

CASE 2 (GUSTAAF): KEEPING DOUBTS TO THEMSELVES OUT OF A SENSE OF LOYALTY

One of my most unsettling experiences occurred in a collaborative research project wherein people with the label "intellectual disabilities" (verstandelijke beperking) were trained to become "experts by experience", so that they might raise their voice for what concerned them – with the aim to create social change. In the Netherlands, "verstandelijke beperking" covers a diverse range of people who need some degree of specialised care and/or support because of a congenital delay in development and sometimes a delay in education. In everyday life, people with this label often face stigmatisation, discrimination and social exclusion.

Soon, I felt remarkably "at home", safe, and appreciated amidst my research partners with experiential expertise. I became increasingly involved in their lives being also consulted for their personal, relational, and financial problems. Something similar happened with some of the people who received the program training. They started sharing various personal stories to an extent that it appeared to me that most of them had little ambition to become expert-by-experience, as defined by the project leaders, but rather were looking for safer, more satisfactory, and more stimulating ways to spend their days.

Although I cannot tell whether I engaged with both my co-researchers and the study participants as a researcher, colleague, supervisor, therapist, or friend, I deeply appreciated these intense forms of personal disclosure. Yet, these (often emotional) disclosures increased my feelings of responsibility for them, thereby fertilizing my growing doubts about the aim of the program: How could any 18-month program, aiming at creating social change, help put down multi-layered, historically interwoven social and structural barriers? Until today, beyond creating a safe and secure environment for the participants concerned, I doubt any impact of the program. Yet, during the whole course of the project, I had major difficulties to articulate these doubts due to my increasing feelings of personal belonging, loyalty, and friendship towards my research partners, the participants, and the project

leaders. I was afraid that my critical reflections would undermine their (partly shared) hopes, and that if I would ever publish about this, I would end up unwillingly betraying them – my group.

Reflecting on this alienating experience of not being able to express fundamental doubts brought me back to what I had experienced almost two decades ago, leaving the orthodox religious community in which I was raised. Even though I was thoroughly personally connected to this community – all my friends, classmates and family members were part of it – from the age of 16, I increasingly experienced a lack of space to express doubts, other than from the excluded and pitiful position of a "sinner". Since my expression of doubts, back then, did not yield encouraging responses, I gradually stopped asking fundamental questions. In hindsight I think that, apart from being juvenile, my strong desire to personally belong had kept me from expressing doubt, back then, and now again.

Out of sense of loyalty, I have postponed writing about this challenging experience for years, despite ongoing doubt about my integrity as a researcher covering up an important (unwanted) research outcome. The reason for being upfront and openly reflexive about this now results from a rather simple and pragmatic insight I gained during our interactive interviewing process: After all this time, my anonymized reflections on this unsettling experience would no longer threaten the precarious start-up of the experts-by-experience group; they were already way past that phase. Realizing this, I could finally do right by the explicit decision I had lived by in every project I am involved in since this one: to share any doubt concerning aim, processes, and outcome. After all, if we, as collaborative researchers do not explicate and try to learn from our inner struggles with collaborative research, who will? Collaborative research needs reflection processes about what is at stake and what is to gain for everyone involved, both professionally and privately, for this helps to clarify what we are actually doing when we work together, why we are doing it, and based on which previous experiences.

Although my doubts in this specific project had kept increasing, I was not able to share them in a mutually satisfactory way with my research partners and the participants. I linked this failure with previous futile attempts to stay both engaged with and accepted by a community that I felt strongly attached to when our perspectives started to diverge. Once again, I had felt personally attached to, as well as trusted and valued by the people I was engaged with. And once again, addressing my growing doubts about a shared narrative appeared to me as defamation and betrayal, as it would unsettle the apparent harmonious relation between us by questioning the legitimacy of the group identity.

Thus, there was little difference between my initial response to emerging fundamental questions in a *private* context two decades ago and in a *professional* context many years later: I kept them to myself. In said collaborative research project, this failure refrained me from productively analysing, what these feelings of discomfort meant for the topic and relations at stake. If I would have kept trying to explicate my doubts, we all might have had a chance to learn more about the possibilities and limits of our collaborative partnership, and its potential to facilitate and contain multivocality. In order to facilitate that in consecutive research projects, I regularly try to challenge myself and the people I collaborate with explicitly to open up about doubts and views concerning why and how we work together, e.g., by writing positionality statements and sharing and inquiring them together (e.g., Muhammad et al., 2014).

CASE 3 (SEBASTIAN): HURT OF BEING IDENTIFIED AS PRIVILEGED AND BEING "CAUGHT AGAIN"

My second case did not happen within the context of a single project but illustrates a phenomenon that occurred to me within various collaborative research relations. During a conference, a researcher with experiential expertise I am working with introduced me to another by saying: "This is Sebastian. He lives in a posh house, he has three children, and is earning as a professor." I was stunned. Certainly, this commentary was true to my reality. Yet, in this moment, it felt to me like a derogatory representation, given the months that both of us had been trying our best to exchange our positions and perspectives and communicating own vulnerabilities.

Years later, I was introduced by another researcher with experiential expertise to a well-known professor with experiential expertise with the words: "This is Sebastian, he is a psychiatrist." Again, I was hurt. Both of us had been invested a lot of energy into talking through various levels of difference, gradually arriving at some forms of commonalities. And now this harsh separation: Here the researchers with experiential expertise, there the psychiatrist. Rigid and unchangeable roles, remaining forever despite of all these efforts.

Collaborating can be painful when it entails being (recurrently) reduced to one's privileges, position of power, and related responsibilities. Even more if this occurs within a relation that had been fought for and grown over months or years. Reflecting on these two instances, I realized that my collaborating may have

stemmed from or evoked the desires of "going native," of getting on in harmony, of creating sameness. Yet, I will ever stay a psychiatrist, even more in relation to a psychiatric survivor. I cannot simply leave this role behind. Despite reflexivity, I will remain an integral part of the psychiatric system with its institutional power dynamics that are deeply embedded within its daily and discursive infrastructures.

Allowing for these unsettling ideas and encounters helped me to level some of my previous disturbances that had frequently occurred to me in collaborative relations. Usually, this lesson of being "a different category" in collaborative relations led to feelings of alienation and detachment. I felt to be "on the other side," leading "another kind of life," a life that fundamentally differs from the persons that I am trying to work with – the people I collaborate with and me in two fundamentally distinct worlds, without ways to overcome what separated us. This lesson, further, was often aligned with another kind of unsettling incident, the one of "having been caught again" by my one-sided perspective, or privileges, or my implicit or overt stigmatizing behaviour or prejudices. Both insights still occur, almost every day during my collaborative work, making it sometimes difficult to tolerate.

An understanding of these unsettling lessons as resulting from structural problems, instead of personal failings, help me to face them, also into the open of my research groups. Such an openness certainly does not change the divide between my research partners with experiential expertise and myself, but it may improve our relationship. Most importantly, it may deepen our understandings and "feelings" about prevailing privileges, the maldistribution of power, and social injustice in the context of research formation, psychiatric institutions, and society at large. It further may elucidate a lot about the identity formation of experiential experts and the place of us non-experiential experts in this context, i.e., a refined understanding about what collaborative relationships may and may not be able to achieve.

CASE 4 (GUSTAAF): NON-VERBAL AND BODILY INTERACTIONS AS/IN KNOWLEDGE PRODUCTION PROCESSES

> Throughout my PhD-research, I engaged in many encounters with people with severe or profound intellectual disabilities (who do not use words to express themselves), determined to gain insight into what was at stake for each of them in their life. I vividly remember meeting a non-speaking research partner in the garden of his residence, for the first time. Since I was not familiar with people who do not speak, I felt a bit uncomfortable as I sat down next to him and greeted him. He appeared not to have noticed me, as he continued playing with a piece of rope in his right hand. I observed him for a while, but then I started to wonder if he was at all interested in my presence. I only just managed to resist an urge to say something, to break the increasingly uncomfortable silence. After a tough couple of minutes, wherein I also fought a tendency to quickly disappear, I softly pulled the rope he was playing with. He looked at me for a few seconds, started smiling and slowly slit his left hand in my sleeve. Resisting a tendency to withdraw from this unusual bodily contact, I let him act. We sat there for a few minutes, skin on skin, exchanging smiles, in complete silence. There and then, although still a bit alienated, shaky, and alert, I somehow felt deeply connected with and acknowledged by this unfamiliar man, and the unfamiliar way he – literally – touched me.
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> Throughout the course of my PhD-research, one of the many things encounters like these made me realize was that how my strong tendency to focus on what is (and can be) verbally expressed and cognitively understood, leaves a huge part of what is (non-verbally) happening and relevant in interactions with others unattended. That insight was helpful to me both as a person and researcher, since I often easily engage in intense verbal and cognitive contact with others in order to make sense, although I regularly end up losing a steady sense of myself, of the other and/or of the environment. This paradoxical experience seems especially pressing with regards to working in academia, in which words and cognition are usually preferred over non-verbal and non-rational ways to interact and to develop understanding, rendering a collaborative researcher with research partners who hardly apply verbality and cognition a peculiar partnership.

In many encounters with non-verbal people with the label "severe or profound intellectual disabilities," I became more aware of the potential of my body's adaptability and connectivity – which gradually helped me to question my stubborn conviction that I could only respond meaningfully to someone in research by applying verbality and cognition. In turn, when I felt invited and acknowledged, this insight helped me to experience with touching, imitating, tapping, pushing, frolicking, or sitting on someone's lap as means to interact and to get to know another (Bos, 2016). In these unusual research situations, I often experienced a profound connection, both within myself and with my communication partner; a rush of unusual certainty – no doubts, but mainly shared being. At the same time, these ways of embodied proximity with another person were unsettling and volatile, as they often occur without words and entail unfamiliar acts and

exchanges for an academic researcher. What is going to happen? What is allowed? Who is leading, who is following? Who is the first to stop, and why? And how do we navigate (i.e., respect, extend and/or violate) cultural, social, and individual boundaries, of which we know that they are often influenced by unchallenged ableist values (Campbell, 2019) and the ability/disability binary (De Schauwer et al., 2020)?

From an epistemic and methodological viewpoint, this case sheds light on some limits of collaborative research, or rather on the borders of what counts as scientific practice in general, i.e. what can and cannot be verbally expressed and cognitively negotiated. As a researcher without experiential expertise, I had to get used to cross the verbal and cognitive imperatives that are predominant in most scientific discourses. Only gradually, I came to conceive collaboration as a mixture of interaction, emergence, motion, disruption, and rebalancing; the involved research partners continuously responding to each other by means of their bodies, emotions, attitudes, words and previous experiences. Consequently, I became increasingly critical of my initial dominant and one-sided position as verbal and cognitive meaning-maker interacting with non-verbal research partners – assigned to capture what could be expressed by academic means and frames of reference – and I tried to experiment with more fitting, non-verbal approaches (e.g. Bos & Abma, 2021). The discussed case, thus, fundamentally questions the scope, assumptions, and relevance of contemporary scientific knowledge production processes, challenging some of its fundamental assumptions, thereby being of high epistemic value to the field of future collaborative research and beyond.

DISCUSSION

This paper offers four experiential cases that aim to demonstrate that engaging personally and emotionally in collaborative research not only may lead to personal struggles and gains, but also may advance its methodological proceedings and epistemic scope. Inspired by Church's critical autobiography (Church, 1995), we introduced the notion of *unsettling encounters* to deliberately emphasize the disturbing and upsetting sides of collaborative interactions, as these in particular may lead to a variety of epistemic and methodological gains. Our main argument is that feelings of unease, confusion, irritation, and discomfort on the side of researchers without experiential expertise may be productive, as they may both cause or follow a change of perspectives and insights concerning the collaboration. In other words, these feelings of unsettlement may result from or lead to an altered relationship between the researchers involved and, thus, improve the theoretical or empirical understanding of the research field or topic at stake.

In this sense, instead of implying an overly pessimistic or languishingly perspective on collaborative relationships, the notion of *unsettling encounters* in collaborative research intends to point at the many (in our opinion so far neglected) possibilities for change that may reside in instances of personal and emotional disturbance and confusion. In contrast, most of the few existing accounts of researchers without experiential expertise that we know of, tend to focus on rather bland, positive experiences of collaborative relationships. A recent series of papers that was published in the field of MH under the umbrella term "ally" (Happell et al., 2018; Happell & Scholz, 2018; Moss et al., 2021; Scholz et al., 2019; Spandler, 2018), reports on various gains of engaging in collaborative research, such as "expanded learning" (Happel et al., 2018), "increased awareness" (Happell & Scholz, 2018), "personal satisfaction" or fulfilment of "social values" (Moss et al., 2021). Confusing or painful feelings, such as shame, embarrassment, or guilt are widely lacking from these accounts, which surprises us, given the frequency of their occurrence in our projects. This trend extends to the field of IDD, where publications about sustainable collaborative relationships mainly focus on the importance of "competencies" (Embregts et al., 2018), "empowerment" (Frankena, 2019), "mutual respect," and "effective communication" (Chalachanová et al., 2020) – a part from a few exceptions, wherein the authors do reflect on their own unease, confusion and doubts in the research process (Woelders, 2020; Woelders et al., 2015).

The widespread omitting of personal reflections from researchers without experiential expertise may be partly due to the rather impersonal and traditional scientific style of many of the accounts we refer to in this paper. Most of them are original papers that report on empirical findings or theoretical subjects. Thus, the positions of the authors, their personal experiences and conditions remain rather unaccounted for. How it feels, for instance, to be trapped in asymmetrical relations, to deal with irreconcilably diverging positions, to give up hard-won power or to leave well-known research routines remains rather opaque in these contributions. Beside this omittance, most of the authors mentioned above fail to report on the methodological or epistemic consequences of their collaborative relationships. Engaging in collaborative relationships may be perceived of as an instance for personal insight and growth (Happell et al., 2018; Moss et al., 2021), yet, without carving out its concrete epistemic or methodological impact on the research itself. Comparably, in the field of IDD, although some efforts have been made in advocating and reflecting on collaborative research partnerships (Nind, 2017; Sergeant & Sandvoort, 2019; Walmsley, 2001; 2004; Walmsley & Johnson, 2003) and on their positive effects on the quality of the research process and outcomes (Frankena, 2019; Puyalto et al., 2016), these often lack extensive reflection

on the connections between personal engagement and the research at stake.

An outstanding exception is the aforementioned autobiography of Church (1995), in which she reflects in depth on the complex interplay between biographical incidents and her research projects, making her research to a rather personal endeavour and vice versa. Another exception is the recent publication, also from the field of MH, by King & Gillard (2019), a joint account of one person with and one without experiential expertise, in which they reflect on the impacts of a racialized identity on their collaborative knowledge production. In line with these scant exceptions, our four cases attempt to demonstrate that the willingness of researchers without experiential expertise to personally engage in collaborative relationships, to reflect on and work with their feelings and personal responses as these might be valuable tools for developing a richer understanding of the research field or topic at stake. At the same time, such an approach may be related to strenuous *emotional labour* (Banks, 2013; 2016; Broznan, 2019; Hochschild, 1983). As also shown by our cases, it may involve the risk of being questioned in partly longstanding assumptions and, thus, may evoke various forms of confrontation and defense, leading to the question if such a way of engagement is truly necessary.

THREE ARGUMENTS FOR ENGAGING IN UNSETTLING ENCOUNTERS

Our position that it is indeed necessary and desirable for researchers without experiential expertise to engage in unsettling encounters with other research partners – despite the difficulties this may entail – can be based upon three arguments for engaging in collaborative research in the first place. First, as also shown by our cases, allowing for unsettling encounters is of *methodological* value, for it keeps the collaborative process of shared knowledge production going, and may even deepen it. Without a responsive, transparent, and reflexive attitude, the involved participants are not able to connect and work together, even more as collaborative research relations usually are characterized by an asymmetrical distribution of power, resources, and different forms of knowledge. It is difficult to build up the trusting and productive teamwork that is needed for this kind of research, if people miss the chance to exchange their professional and personal motives for engaging, their goals and backgrounds (Muhammad et al., 2014). Personal, emotional involvement are a large part of this process, and may well unsettle the persons concerned and the way they relate to each other.

Second, engaging in unsettling encounters may be perceived as an *epistemic* necessity. After all, collaborative research projects usually aim at changing the concrete conditions of marginalized groups (Bradbury, 2015), from which researchers *with* experiential expertise usually are part of, whilst we as their counterparts usually are not (King & Gillard, 2019). Responsivity towards, transparency about and reflecting on power asymmetries and distinct perspectives on the micro-level of any collaboration are often valuable steps to better analyse the wider political, societal, and cultural concerns that are usually at the centre of the research (Ellis, 2004; Wright & Kongats, 2019). Thus, allowing for unsettling encounters often leads to research designs which are embedded in concrete experiences, situations, and problem definitions, potentially yielding outcomes that are more useful to the people and the situation of concern.

Third, and more conceptually, allowing for unsettling encounters is essential to do justice to some of the main *principles* of collaborative research. Since collaboration and participation are, by definition, relational phenomena, they involve experiential forms of knowledge that do not come compartmentalized but are bound to situated narratives and emotionally charged context. Thus, working in collaborative projects requires reflecting on power asymmetries (Carr, 2019; Groot & Abma, 2019), pre-reflexive tendencies (Bos & Abma, 2021; Happell et al., 2018), and performing "passibility", i.e. postponing judgement despite reflexive tensions and suffering (Bos & Kal, 2016; Lyotard, 1988), in order to facilitate process-oriented outcomes such as mutual learning, personal growth, or empowerment (Banks & Brydon-Miller, 2019; Wakeford & Sanchez Rodriguez, 2018; Wright & Kongats, 2019). If we take these principles seriously, we cannot submit to collaborative research as mere scientific technocrats, who simply regards a distinct set of methods, but must engage as human beings with our personal history and biographical contingencies. After all, any unwillingness by researchers without experiential expertise to engage in unsettling encounters risks tokenism as well reproducing the status quo, in potentially replicating common experiences of their research partners witch experiential expertise of not being heard and seen, being excluded, not belonging, or not being recognized, alienated, and being separated in a parallel world (Boumans, 2012; Carr, 2019; Woelders et al., 2015). In contrast, stimulating a responsive and reflexive engagement that is open to criticism has the potential to expose and question multi-layered experiences of social inequality and injustice that, if not acknowledged, tend to subvert common aims and principles of collaborative research, despite all good intentions.

UNSETTLING THE PRIVATE-PROFESSIONAL DIVIDE

Our advocating for unsettling encounters in collaborative research immediately brings into question the divide between "private" and "professional" interactions (Church, 1995). In this context, we understand

professional interactions as rather formalized, goal-oriented, strategic, technical, and embedded within explicit normative structures like education, contracts, economic regulations, codes of conduct, and formal positions of power (Habermas, 1981/1995). In contrast, *private* relations are usually voluntary (if not family) and tend to be acted out within a realm of shared interests, values, and experiential backgrounds.

Even though these accounts are reductionist and artificial, and reflect and reinforce stereotypes, they also help to understand what is already at stake in any collaborative research partnership. First, they show that working together as researchers with and without experiential expertise integrates various aspects of both professional and private relations, transforming them into complex interpersonal amalgams – whether we like it or not. Crucially, the many ambivalences, insecurities, and questions that may emerge on both sides of the relation (e.g. regarding privacy, distance, judgment), can be perceived as reasons why collaborative partnerships are destabilizing and undesirable, as well as rewarding and productive. Consequently, whether the research partners try to keep this private-professional divide intact or embrace its destabilization, largely depends on how they look at themselves in relation to others in the research context, and on the extent to which each of them is willing to do right by what matters to everyone involved.

Second, our reductionist distinction between "private" and "professional" is also useful to elucidate one of the central pitfalls of collaborative research relations: power asymmetries. As we all know, one of the most distinctive contributions of researchers with experiential expertise is to apply experiential expertise, often including the sharing of personal narratives and rather intimate accounts. Yet, if we, as researchers without experiential expertise, stick to a rather technical way of engaging, we add to problematic power asymmetries that are at stake anyway. In other words: there cannot be a more balanced collaborative relation (let alone a more socially equal and just one), if one partner opens-up while the other does not. Hence, the way anyone navigates this private-professional divide in collaborative research is connected to their epistemological and normative-ethical lens.

AN EPISTEMOLOGICAL AND NORMATIVE-ETHICAL LENS FOR UNSETTLING ENCOUNTERS

How does our plea for unsettling encounters in collaborative research relate to contemporary epistemological discourses and scientific theories? Which conceptual frames of reference do we draw on to legitimate that (a) our claim that collaborative research needs unsettling encounters is epistemologically valid; and (b) this operationalization of collaborative research also meets the requirements of quality standards, allowing for critical appraisal? Answers to these questions are essential, as collaborative research approaches still fight for scientific acknowledgement, usually refraining from meeting traditionally adhered quality criteria like "neutrality," "generalizability," "rigor," "reliability," "objectivity," and "scientific abstinence" (Guba & Lincoln, 1989), that have a long (medical) history in both disciplinary fields of MH and IDD.

Various conceptualizations of quality criteria for collaborative research approaches make clear that their appraisal must follow distinct standards. Principles such as "trustworthiness", "persuasiveness," "applicability," "consistency," "authenticity," and "critical reflexivity" (Abma et al., 2019; Ellis, 2004; Lincoln & Guba, 1985; Schön, 1983; Smaling, 2008; Stake, 1975; Wakeford & Sanchez Rodriguez, 2018) seem to fit well with our understanding of collaborative research. This also applies to the criteria "catalytic validity" and "practical relevance," which indicate a project's potential to transform the participants and the field of concern (Lincoln & Guba, 1986).

Underlying is a wealth of (normative-ethical) concepts and theories that mostly stem from the social sciences and humanities, considering any reality – including any scientific reality, their definitions, and findings – as relationally co-created, instead of pre-given or deterministically predefined (Gergen, 2012; Hosking & Bouwen, 2000; Leget et al., 2017). The world we live in is complex and multiple (Kunneman, 2017; Merleau-Ponty (1945/1962), and we construct and produce knowledge in interaction with others and our context (Belenky et al., 1986; Thompson & Varela, 2001; Van Manen & Li, 2002). Thus, any knowledge production process is *relational*, *situated*, *partial* and *political*; we cannot investigate something "from above," but are always caught in our perspectives, motivations, and frames of reference (Denzin, 2000; Feder-Kittay, 2009; Tronto, 1993; Waldenfels, 2011). Our plea for unsettling encounters as a defining phenomenon in collaborative research aligns well with such an epistemological and normative-ethical perception. If each of us is indeed bound to their own lifeworld and past and present experiences, collaborative research does neither represent an objective, distant and a-political way of knowledge production, nor a linear, smooth, or harmonious way of democratic knowledge creation. Instead, it involves highly entangled and multiple positioned forms of engaging with one another. In that, we build on and extend empirical and conceptual work about *critical reflexivity* (Muhammad et al., 2014) and *moral* and *cultural humility* (Young, 1997; Tervalon & Murray-García, 1998). For us, researchers without experiential expertise in the fields of MH and IDD, unsettling encounters (including the reflection processes they provoke) adhere to the very core and focus of collaborative research: they keep confronting, challenging and questioning us how we are constitutive

part of the very structures we want to change while collaborating, thinking and writing in favour of more social justice and equality.

CONCLUDING COMMENTS

LIMITATIONS AND FUTURE RESEARCH

We deliberately engaged in our interactive interviewing process without involving researchers with experiential expertise, even though we know that, in comparison, we hold a privileged position that enables us to get "our voices" heard more easily. Yet, in this paper we tried to avoid speaking from such a "position above" in which personal experiences, feelings, and conflicts largely remain un-thematized. On the contrary, we intended to argue that personal reflections of "so-called" researchers without experiential expertise essentially belong to the fields of collaborative research – also on the level of a publication – for they enhance their quality in terms of critical reflexivity, trustworthiness, transparency, and authenticity. Still, we hope that our analysis and reflections may be also of value for researchers *with* experiential expertise, who usually are equally, or even more exposed to unsettling experiences within collaborative research practices (Carr, 2019). After all, their lives and perspectives are primarily at stake in this kind of research, with the result that they are less in the position to circumvent the emotional labour involved. In future research, it might be interesting to incorporate team reflections on how to navigate mutual unsettlement in collaborations between people with and without experiential expertise.

Fundamental to our reflections in this paper was the desire to explore ways to strengthen researchers without experiential expertise in their intentions to engage in collaborative research. In this sense, advocating for approaching collaborative research as a practice with potentially unsettling encounters, instead of primarily enacting a set of distinct methods and techniques, we position our paper clearly in developing this field of research (e.g., Muhammad et al., 2014). Thereby, we are aware that continuous focussing on feelings of unsettlement might unwillingly overshadow a helpful sense of community and harmony – and thereby risks fragmentizing, or even jeopardizing, (short term) collaborative efforts. However, without allowing for being unsettled and disturbed as a person, and trying to learn from that, we, as researchers without experiential expertise risk to miss out some of the major methodological and epistemic potentials of this kind of research. Even more, we risk reproducing power differentials and relations of injustice, failing to move towards (long term) social change.

In future research, the question to what extent collaborative partnerships are an effective means for creating this social change makes the necessity of unsettling encounters and concurring reflection processes on feelings of unease, confusion and discomfort, even more pressing. In quite a few of our previous projects, we had the impression that our collaboration at best temporarily and artificially achieved to block out existing (power) asymmetries, rather adding to a fetishizing of some bourgeois desires by alluding to, and thereby reproducing distinctions between "us" and "them". On the other hand, do we have another option than trying it? Engaging and exposing ourselves as researchers without experiential expertise in encounters that may deeply unsettle ourselves and who we are in relation to the people we collaborate with appears to be the only credible way forward, leaving aside the possibilities for user-controlled research (Russo, 2012). By emphasizing this need for ongoing reflection on what is personally at stake for researchers without experiential expertise, we aim to extend on contemporary participatory research ethics. As mentioned before, we hope that such emphasis may yield more insight into what helps and hinders the social and societal change we strive for in our collaborations. After all, as researchers without experiential expertise, we are part of the very communities and societies that we want to change.

COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

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