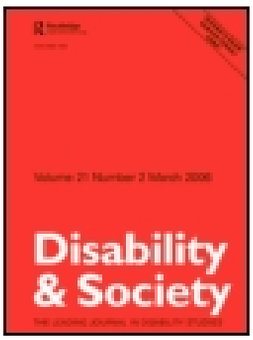

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ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/cdso20

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To cite this article: Corinne Lajoie , Justine Fortin & Eric Racine (2020): Lived experiences of participation in mental health research in Canada: breaking the glass wall, Disability & Society, DOI: 10.1080/09687599.2020.1833313

To link to this article: https://doi.org/10.1080/09687599.2020.1833313

Published online: 14 Oct 2020.

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https://doi.org/10.1080/09687599.2020.1833313

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Lived experiences of participation in mental health research in Canada: breaking the glass wall

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ABSTRACT

Research participants are crucial to the entire research enterprise, but they are still predominantly conceived as mostly passive, 'silent' partners in the field of research ethics. Participants generally have very limited opportunities to share their lived experiences of participation in research and their views about the ethics of research. This gap is particularly concerning for research participants whose agency is already undermined by unjust social structures, such as individuals living with mental illness. Our study investigates the perspectives on research of mental health research participants and mental health advocates in Canada. We found that many participants had positive experiences of participation in research and valued their experience. The positive impacts of research participation, however, depend the willingness of researchers to actively create an accessible and respectful research environment.

ARTICLE HISTORY
Received 10 April 2020
Accepted 3 October 2020

KEYWORDS
Mental health research; research ethics; lived experience; mental illness; research participation

Points of interest

- People with mental illness who participate in research projects do not often get to talk about their experiences. We think that this is a mistake and that researchers should learn from them.
- We interviewed 14 research participants and individuals who work to defend the rights of people with mental illness.
- The research participants said that participating in research had made them feel good. It made them feel respected, valued, and listened to.
- Participants do not want to feel like "things" or "objects" behind a glass wall. They want to be treated as equals.

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Details of any clinical trial registrations: N/A

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- This research is important because it shows that participating in research can be a positive experience for people with mental illness.

Introduction

Research participants are crucial to the entire research enterprise, but they are still predominantly conceived as mostly passive, 'silent partners' in the field of research ethics (Dresser 2006). They generally have very limited opportunities to share their experiences of participation in research and their views about what should constitute ethical research practice. This gap is particularly concerning for research participants whose epistemic agency is already undermined by unjust social structures, such as individuals living with mental illness. Indeed, contentious debates over the participation in research of individuals living with mental illness are longstanding in the research ethics literature (Bracken-Roche et al. 2017). Several policies and guidelines claim that their participation warrants specific concerns and protections. As a result, they are identified by research ethics committees as "vulnerable" participants (Bracken-Roche, Bell, and Racine 2016; DuBois et al. 2012; Bell et al. 2014).

Recent studies of the concept of vulnerability, however, reveal that there is no consensus about the meaning and function of this term in established international policies (Bracken-Roche et al. 2017; Tee and Lathlean 2004) and in research contexts (Sengupta et al. 2010; Lajoie, Corinne et al. 2020). It appears, instead, that unverified (and sometimes paternalistic) assumptions are being made about the needs and capacities of individuals living with mental illness (Bracken-Roche et al. 2017). A recent study of participant perspectives on the notion of vulnerability revealed that many are wary of its over-protective and discriminatory undertones (Lajoie, Corinne, Justine Fortin and Eric Racine 2019). Relatedly, studies have shown that the potentially adverse effects of mental health research participation are largely overestimated in the literature (Jorm, Kelly, and Morgan 2007). Without a doubt, assuring the safety and wellbeing of research participants must remain a linchpin of research ethics. However, these findings reveal that the field of research ethics still has a lot to learn from research participants, and in particular from those who have been historically silenced. (Bracken-Roche, Bell, and Racine 2016; Cascio and Racine 2018; Racine & Bracken-Roche 2019).

Fortunately, outdated views about the passive role of research participants are slowly changing. On the one hand, participants are increasingly recognized as key actors in processes of knowledge-production. Recent research emphasizes the importance of empowering and involving participants throughout the research process (Cascio, Weiss, and Racine 2020). This must be done by implementing accessible research methods developed in collaboration with relevant stakeholders (Dee-Price et al. 2020). On the other hand,

long-established assumptions about the "vulnerability" of mental health research participants are being called into question. In the context of mental health research, this impulse has led to important inquiries about the perspectives on mental health research of individuals living with mental illness (Taylor et al. 2010; Andrighetti, Semaka, and Austin 2017; Boothroyd 2000; Owen et al. 2016; Faulkner 2017; Carr 2019; Jaffe et al. 2015). Our study is directly motivated by these shifts: our aims are (1) to enrich our understanding of lived experiences of participation in mental health research and (2) to help researchers and other relevant parties develop research practices that are informed by the lived knowledge of participants themselves. Inequalities of power between 'researchers' and 'participants' (or 'subjects' and 'objects' of knowledge) have long been the norm in the field of research ethics. While there have been efforts to 'break the glass wall' between both spheres, these dichotomies persist. This study contributes to recent efforts to break the metaphorical "glass wall" between researchers and participants by centering the perspectives of individuals living with mental illness and mental health advocates. We interviewed 14 mental health research participants and mental health advocates in Canada to gain insights about their perspectives on mental health research.

Methods

The results presented here are part of a broader research project investigating the notion of vulnerability in mental health research from the perspective of relevant stakeholders (Lajoie, Corinne et al. 2019, 2020). As part of this broader project, we conducted interviews with mental health research participants and mental health advocates. The findings reported in this paper pertain to a section of the interview which asked participants to reflect on their experience(s) of participating in research and/or to share their perspectives on research as mental health advocates. We received ethics approval for this project from our research institution.

Context of research project

This study was conducted by three researchers of the Pragmatic Health Ethics Research Unit, a bilingual (French/English) interdisciplinary research group based at the Montreal Clinical Research Institute in Quebec, Canada. The authors are respectively trained in philosophy (especially phenomenology) [CL], psychology [JF], and neuroethics and health ethics [ER].

Participant recruitment

We recruited participants through a combination of purposive sampling and snowballing. We contacted mental health organizations by email to ask them

to share our call for participants, posted the call for participants on the social media pages of local mental health support groups and advocacy group, and invited research participants to recruit other potential participants. We sought two types of participants: (1) individuals who self-identified as living with mental illness and who had previously participated in mental health research and (2) individuals who self-identified as mental health advocates (with these categories, of course, potentially overlapping). To be eligible, participants also had to be 18 years of age or older; be able to communicate in French or in English; and understand and consent to the terms of the study. The financial compensation for this study was fifty (50) Canadian dollars.

Our use of the term "mental health advocate" designates individuals who self-identify as working in an official capacity to represent the rights and interests of individuals with mental illness and accompany them in important life activities (e.g. employment searches, care and treatment, educational opportunities, etc.). Our use of the term "mental health research participants" designates individuals who self-identify as having participated in at least one research project concerned with mental health or mental illness (e.g. health services research, service-user or survivor-led research, community-based participatory research, etc.).

Interviews

The semi-structured interviews took place either by phone ($n = 4$) or face-to-face ($n = 10$) in a private office at our research unit, depending on the preferences of each participant. Interviews were conducted in French ($n = 13$) and in English ($n = 1$) by the first author [CL]. We used the following open-ended questions as discussion prompts (we asked questions 1-4 to research participants and question 4 to mental health advocates):

1. How would you describe your past experience(s) of participation in research?
2. What elements of your past research experience(s) did you like or dislike (e.g., attitudes from researchers, specific accommodations, modes of communication, use of technologies, etc.)? What elements made you feel comfortable or uncomfortable?
3. Why did you choose to participate in a research project (then and/or now)?
4. What do you think researchers can do to create a positive research experience for mental health research participants? What should they [researchers] avoid doing?

Data analysis

We used an interpretive phenomenological approach to analyse and annotate interviews. Interpretive phenomenological analysis is particularly well suited to examine complex and emotionally charged topics, such as lived

experiences of mental illness and mental health research participation. A phenomenological stance seeks to uncover how participants describe and make sense of their own experiences. This methodological approach encourages an open, questioning stance at every stage of the project, including regarding our own perspectives and prejudices as researchers (Zahavi and Martiny 2019). We believe that enlisting reflexivity as researchers can "substantially enhance the accuracy and ethical quality of social research" (Goldstein 2017, 149). A reflexive approach reminds us that research is not a disembodied, intellectual process; rather, it is a deeply relational and contextual experience in which researchers and participants are mutually involved.

The researcher who conducted all 14 interviews for this study [CL] is diagnosed with severe mental illness and has a history of hospitalization in psychiatric settings. Her personal history generated a deep sense of purpose and personal connection with this research project. Her affective involvement in this project was not "neutralized by awareness" (Goldstein 2017, 153); it required her to pay close attention to her own emotional responses throughout the interviews and to her role in the research encounter. To date, most literature on mental health research is written from the perspective of researchers who do not disclose living with mental illness. As Banfield et al. (2018) argue, however, involving lived experience researchers can contribute to "[break] down the dichotomy between 'lay [mental health consumer]' and 'academic researcher'" (1220) and offer avenues for questioning and transforming power dynamics in mental health research.

Data presentation

To present our findings, we drew on the methodological device for crafting stories developed by Crowther et al. (2017). Upon close analysis of interview transcripts, the lead author created short narrative stories describing each interview. We complemented these descriptive narratives with excerpts taken from verbatim data that were particularly evocative and important. These narratives were then edited through an iterative consultation process with the second and third author.

We attributed aliases to participants based on their self-expressed gender identification. When relevant, we included some of the comments and questions formulated by the interviewer [CL] to illustrate the dialogic nature of the exchange. Our use of the first person singular in the following section reflects her point of view throughout these interviews.

Results

Lucie

Lucie shared two experiences of participation in research. She described keeping a good memory of her first experience but grew seemingly more

uncomfortable when recounting her second research experience at a local psychiatric hospital. She told me that this second interview was more "complicated" than the first one. She described the interviewer's questions as "subtle" and "raw", and as "trick questions". When I asked what made her feel like they were "trick questions", she told me that she felt as if she had to sound "intelligent" and provide "clear" answers that would be "fruitful" for the researcher who interviewed her. Lucie did not feel comfortable with this researcher, notably because their questions felt intimidating.

We returned to the topic of her first interview and Lucie smiled when I asked her what she had liked most about it:

> **Lucie:** Well, when she turned on the recorder. Just like now, when you turned on the recorder.
>
> **Corinne:** What did you like about it?
>
> **Lucie:** I liked it because it was flattering, you know? It was like: "You're going to be fine. Answer this interviewer properly, you'll see, you won't be disappointed." Yeah.

We talked about the fact that this little gesture (i.e. being recorded) had made her feel valued and important. At the end of our interview, I shared with Lucie how meaningful it was for me, as a researcher and a person, to learn about her perspective. Reciprocally, Lucie told me that she had also gained something at a personal level from participating in my study. She said that her path had "flourished" and was now more "open". While the financial compensation played a part in her decision to participate in studies, she explained to me that they also have an "emotional and even a sentimental [value]" for her. She further explained: "I was thinking to myself, this is going to help me get my mind off other things, it's going to help me. And it's going to be helpful, you know. This isn't just a little knickknack for me, I take it to heart."

Marie

Marie had previously participated in a research project at a local psychiatric hospital. She told me that she was hospitalized shortly after participating in this project and that she "saw the consequences" of her participation. I asked if she could explain what she meant by this. Marie said that she worried that her answers to the interviewers had ultimately had a negative impact on services at the hospital. Long after participating, she still wondered if it was her fault that things had not changed for the better for her and for her institutionalized peers.

I asked her what she thought would be the most important elements to include if one was running a study. She said that it was essential that the implications of the study be clearly explained to research participants.

Angeline

Angeline was very reflexive about her own relationship to research. She described in rich detail the process of acceptance and self-discovery that it had generated for her. Angeline was hospitalized the first time she participated in a research project, many years earlier. Since then, she has participated in various other projects. Angeline described her numerous experiences of participation in research as an emotional journey and a process of self-discovery. Participating in research eventually helped her find a balance within herself and learn to cope with symptoms of panic and paranoia. She explained: "Sometimes it's like [I would ask myself]: 'Am I being used? Am I part of a system where I'm a guinea pig?' You start from frustration, acceptation, curiosity, and then [you arrive at] understanding." We discussed research practices more generally and I asked her what it would mean for research participants to have their rights respected:

> **Angeline:** It would literally mean asking us questions. You know, when they don't ask whether or not we're comfortable, it's just theoretical, medical, and: "Okay, you're diagnosed like this, so you take this, this, this, and that's it."
>
> **Corinne:** We take some things for granted?
>
> **Angeline:** Yes. That's what I call the clinical side. It's the cold side of things that makes you a sick ball. They probe and prod you, and sometimes you feel like they have absolutely no idea where they're doing. It's the side that makes you sort of lose your balance.

Angeline explained that involving participants living with mental illness in the elaboration of studies about their life could alleviate the impression of being "judged from the outside." Furthermore, elements such as a researcher's tone, their manner of expressing themselves, their facial expression, or the questions that they ask can make the difference between a "warm" and a "cold" (or "clinical") attitude. When participants are treated as equals, a true experience of reciprocity and "a transfer of information and of reasoning" can happen. However, this experience requires caution and confers an important responsibility on researchers: "Above all, to not mix the cards that the person brings to the table. When we share data with researchers because of our life experience, it's *our* life experience that is dissected, probed and prodded."

Danielle

For Danielle, one of the most important element of mental health research is providing participants with all the support that they might need (e.g. check-ins, lists of psychosocial resources, follow-ups, etc.). Research projects that involve revisiting difficult life experiences can be very hard, but, for Danielle,

it's also "part of the game". I asked her if she thinks that mental health research raises a unique set of ethical concerns. She replied that the main element that came to mind for her was the difficulty of reaching a sample of participants that is really representative. For example, she explained that it might have been easier to find and recruit her because she is "more articulated, and more educated". To the contrary, people who are isolated, less verbally articulate, or who have been ill for a long time and are particularly vulnerable, might be more difficult to reach.

Nicole

In her role as a peer helper in a mental health support network, Nicole accompanies and guides individuals living with mental illness through their life activities. She understands their experiences and can relate to them, she explained, because she herself has previously been medicalized and hospitalized in psychiatric settings. Having dealt with mental illness and psychosis, "she can very well understand [emotional suffering] because she lived through it herself." This allows her to share strategies of self-preservation with her peers.

Nicole's work focused on holistic approaches to mental health care. She shared with me her dissatisfaction with traditional biomedical and clinical approaches. She explained that she was motivated to participate in research by her desire to see approaches evolve to better meet the needs of individuals living with mental illness. For Nicole, elements that might help make a participant more comfortable and feel like they are treated as an equal could include: validating with each person that they feel comfortable; asking participants where they would like to meet; sitting next to them rather than across from them; and ensuring that participants are sitting near closely accessible and non-obstructed exits to prevent them from feeling trapped.

Sylviane

Over the course of our interview, Sylviane mentioned twice that she would like to have a job and be able to work but that she was too "disorganized" for that to be possible. She explained that participating in research studies helped her financially and made her feel helpful to society. When we discussed her experiences of research participation, Sylviane told me that she was particularly happy to receive a financial compensation.

I later asked her what she thought was the worst mistake a researcher could do with a mentally ill research participant:

> **Sylviane:** To judge you. To look at you … like a nuisance. It's a big word, huh? […] As if my mental health was like a nuisance. […] I've seen people like that, and it, like, shocked me so much.

Corinne: It's an interesting term that you're using, 'nuisance'.

Sylviane: Yeah, that's right, but unfortunately, we're labelled a lot, a lot.

Corinne: When you say "we're labelled", what are the labels that you think people attribute to individuals living with mental illness?

Sylviane: I don't have the exact word, but it's literally too much. As in, I don't do anything with my life. [...] I'm useless. Everyone, whether they bring a little or they bring a lot, has to be protected and well supported.

Reflecting on the harms produced by these labels and judgements, Sylviane shared with me that her mother has mental health issues. She had judged her mother a lot in the past and was never close to her. Today, she told me, she stands on the other side of the shore and faces prejudice of her own because of her mental illness.

Jiaying

Jiaying was one of a few interview participants who had been enrolled in a local arts rehabilitation program for youth living with mental illness. She was first introduced to this program through her participation in another research project while she was an undergraduate student. When she first enrolled in the arts program, she did not clearly know whether she was enrolling in a research project or simply enlisting in a rehabilitation program. Jiaying's confusion persisted long after she began the program. She consulted the psychiatrist in charge of the program for three years after enrolling, but told me that she never received an official diagnosis and was not sure whether these meetings counted as a part of a research project or not. Although she felt very positively about participating in the arts program overall, she reported that it was "a bit confusing" to know exactly what was going on and that things were "not necessarily 100% clear."

Over the course of the program, Jiaying particularly appreciated having "a safety net around her" during interviews and workshops, for example by having a doctor or a psychologist on site that was aware of her medical history and could "assure the group's well-being." This safety net, for Jiaying, did not need to be "explicit" and could in fact remain very subtle. Nonetheless, she explained, "there are moments that are more difficult than others and it's important to have someone present."

Mélodie

Before our interview, Mélodie disclosed to me that she had been anxious about our meeting. Although she eased up during the course of the interview, she was initially anxious about meeting me at the research center (although she preferred this option to meeting elsewhere). We had a number

of discussions (over email and phone) about how to get to the research center, what the facilities would look like (e.g. elevators, stairs, location of the rooms), and what to expect when she arrived (e.g. checking-in at the security desk, waiting for me in the lobby). She later mentioned that she had appreciated our discussions, when we spoke of research practices later in the interview.

For Mélodie, the most important element of mental health research is making participants feel at ease and comfortable (e.g. by actively reminding participants that they can take breaks without waiting for them to bring it up, asking them where they would like to meet or how they would prefer to speak, offering clear explanations about the research process, and having a non-judgmental attitude). She explained that researchers should meet participants in a quiet space that allowed them to focus on the interview. Additionally, they should not make participants worry about time limits or rush through questions.

Mélodie explained that she suffers from severe anxiety; as such, she would find it difficult to ask for help or for more explanations if she did not understand the research project that she was participating in. She was confused, for example, the first time she participated in a research project: "Since I was at the hospital at the time, I wasn't 100% well, so I was a little bit lost. You know, like, I accepted, but I wasn't there 100%. [...] I don't feel like [the researcher] explained the thing well enough, the research project. Maybe that's why it's so confused in my head."

Augustina

Augustina coordinated a community organization offering support and services to individuals living with mental illness. During our interview, she told me that one of the most important things to consider was to individualize our approach to meet each person's needs. This requires that we be willing to put in the additional work that might be required (e.g. providing more time to answer questions or offering follow-ups). Individuals living with mental illness might find it demanding to participate in certain activities and attend appointments. Thus, Augustina emphasized the importance of making things as simple and flexible as possible. She also shared recommendations for building rapport and an atmosphere of reciprocity, such as getting to appointments at the same time as participants and entering the room with them rather than having them enter an office alone, taking a few minutes to put them at ease by chatting colloquially before officially starting a meeting or interview, and explaining why the researcher is taking notes and what her role is before pulling out a notepad and starting to write.

Marie-Anne

Marie-Anne worked as a patient advocate in a community organization offering first response mental health training. She had also participated as a mental health patient in a form of therapy that might have been research related, although she was unsure about this. She told me that one of the things that she found particularly important was for participants to receive validation: "We often feel misunderstood. Both people who have mental health issues and those who don't. […] But particularly when someone isn't feeling too well, [researchers] can ask the question: 'Am I understanding correctly what you're trying to tell me? Explain to me how you really feel.'" Creating spaces for people to feel listened to and understood when they share their experiences can make mental illness less "frightening". Ultimately, Marie-Anne told me that getting someone to open up and provide "real answers" requires a researcher with a "really humane" approach who is willing to "take their time and take the time to listen." I asked Marie-Anne how she felt about specific concerns regarding the protection of participants with mental illness in research contexts:

> **Marie-Anne:** You're never forcing anyone, you know. […] If there's someone that knows exactly what we feel like when we get told that, it's us. […] There's so much stuff, so many clichés that we get told. […] It always undermines us. We're always undermined, so if at some point we get offered a space to express ourselves, then let us do it. They'll see that we're not dangerous.
>
> **Corinne:** Yes. What I also understand from what you're telling me is that being excluded from a research project because of mental health issues only adds to the isolation.
>
> **Marie-Anne:** Yeah, and my big problem in life is rejection. So each time I'm confronted to rejection, I start telling myself: "I'm not worth anything. I can't even express myself on what I'm going through, so I'm not really worth it."

Judy

When I asked Judy what it might take to create a safe and comfortable research environment, she offered as a counterexample her personal experience of receiving visits from doctors and residents in the psychiatric ward: "I often felt like it was like, you're the patient, but there's a really big distance. And sometimes they would even talk about me in the third person, but I was there. So, that was like, awful and alienating." Judy described this experience as "this feeling of, like, a glass wall literally with doctors and then patients on the other side, and you felt like an animal." To the contrary, the atmosphere in some of the therapy groups that she participated in outside the hospital encouraged more genuine connections and involved therapists and students that were "kind and patient and just very human". She

explained to me how important it was to her to be treated with compassion and as an equal: "It's easy to say, but a lot of people don't do that."

Judy offered various recommendations for mental health researchers. She specified that most of her recommendations come down to always asking participants and validating with them what they prefer and what they feel comfortable with. Some participants might want access to consent forms in advance, others might feel anxious about meeting someone new in a new place, or worry about answering accurately, etc. For Judy, researchers can alleviate this burden by checking in with participants: "You could even ask, you know, are these conditions okay for you? Is there anything I should know that you'd rather we know?" Researchers must be open to making adjustments when needed. Although discussions around access barriers, needs, and capacities are difficult, Judy felt that they were necessary:

> **Judy:** It's a conversation that we feel embarrassed to have, but it's important.
>
> **Corinne:** It's just so odd because it's so simple at the same time to ask someone that.
>
> **Judy:** Yeah. And if nobody asks you, then you won't say it. I mean, I've learned to say it with time, but if there were certain things I was uncomfortable with when I was ill, I used to not say it and just suffer. But now, I tell people. And I make sure if I go meet someone who I know has depression or … I know it's hard for them to get out of the house, so they might rather speak on the phone. Or I know it's hard for them to answer the phone, so you might have to reschedule your interview five times, you know? But they want to do it, and they will eventually do it […].

Pénélope

Pénélope shared with me that the sense of participating in society as a full citizen and human being had been important to her since childhood. By participating in research, she felt that she was offered a space to contribute to changing popular understandings of mental illness and what it means to live with mental health issues. She felt particularly concerned about the deficits of credibility and the experiences of stigma faced by individuals living with mental illness. When attempting to voice their experience, these individuals face barriers that lead them to "remain silent because they are not being believed."

Pénélope had participated in a research project at a community centre near her home. She described to me her previous experiences of homelessness and of being harmed by people around her. While recovering from this trauma, she found human contact extremely difficult and could not open herself up to others for years. Her experience of participating in research had marked an important turning point. As she revisited this experience during the course of our interview, she expressed her gratitude at being offered the

opportunity to participate and be fully listened to: "In research, what touched me the most was when I was asked questions [...] and then I had a person that really seemed to be listening to me, and to believe what I was expressing. [...] And it was the first time that someone from the outside was coming to our community centre to listen and to believe what it was that we were living or how we had lived it [...]."

For Pénélope, the attitudes of researchers toward participants, especially the capacity not to look at individuals living with mental illness with prejudice and like they are afraid of them, facilitates research interactions. Pénélope also described the importance of validating the claims of participants rather than doubting our questioning them, and making sure that they feel like they are truly being understood. Participants who have never been listened to are vulnerable to some forms of coercion and abuse: "the first time that [someone that has never been offered acceptation, tools, and support is recognized] as a human being, they're willing to buy into everything [the person listening to them] says or does." She suggested that it is sometimes best for participants to be accompanied by someone that understands them and that they trust to protect them. Much like researchers and specialists have "their" language, "individuals living with mental illness also have their language" and can look out for each other.

Discussion

The aim of this study was to investigate the perspectives on research of mental research participants and mental health advocates. We discuss our findings along five categories: (1) the positive impacts that participating in research can have on the lives of participants; (2) the negative (or potentially negative) implications that may result from research participation; (3) the importance of clear communication throughout the research process; (4) the differences observed by participants between impersonal 'clinical' approaches and compassionate, respectful approaches; and, finally (5) the epistemic deficits, stigma, and prejudices experienced by individuals living with mental illness, including in research contexts.

Positive impacts of research participation

A number of participants (Lucie, Angeline, Sylviane, Pénélope) emphasized the positive impacts on their lives of participating in research. Research offered them a space where they felt important, valued, and listened to. They explained that participating in research allowed them to discover new parts of themselves, feel helpful and important, develop a sense of belonging in society, and progress on their "path" in life. Some mentioned that the financial compensation played a role in their decision to participate and

fostered a sense of recognition (Sylviane, Lucie). For most, the decision to participate in research was deeply personal. As Lucie explained it, participating in research was not simply a "knickknack" or a distraction from her daily life: it was a task that she "[took] it to heart". In our understanding, Lucie was flattered to be recorded because this made her feel like the seriousness of her commitment was being reciprocated by the researcher's interest. Her account can be read in parallel with Marie-Anne's observation that obtaining recognition and feeling validated is especially meaningful for individuals who have historically been ignored and silenced. Participants reflected positively on experiences of research when they felt respected and listened to.

Our findings echo recent findings about the lived experiences of mental health research participants. To reiterate a point made in the introduction to this paper, although many theoretical concerns have been raised about the vulnerability of individuals with mental illness in research contexts, empirical findings suggest that these worries are often out of synch with the actual experiences of participants themselves. Indeed, current data indicates that mental health research (including suicide-focused research) is *not* associated with significant distress or increased harm (Carter et al. 2020; Batterham et al. 2018). Instead, research has shown that most participants reflect positively on their research experiences, even when they concern emotionally charged topics (Andrighetti, Semaka, and Austin 2017; Boothroyd 2000; Owen et al. 2016; Taylor et al. 2010; Andriessen et al. 2018).

Participating in research can be a valuable experience and offer participants a space to be listened and to take pride in sharing their knowledge and experiences. These positive impacts must be considered by researchers and research ethics boards when decisions are being made about the impacts associated with research projects (Lakeman et al. 2013).

Negative (or potentially negative) impacts of research participation

In our study, few participants disclosed negative experiences of participation in research. For those who did (Lucie, Marie), however, these past experiences seemed to have left a lasting impression. Marie, for example, recalled feeling anxious about the implications of her answers for psychiatric service offerings in the hospital. She worried that she might have been responsible for things getting worse. At the time of our conversation, these worries still occupied her. Lucie also reported a negative research experience during which she felt made inadequate and nervous. She described feeling like she had been tricked into answering questions she did not understand. Lastly, although Pénélope did not disclose a negative experience of research participation, she raised the worry that participants who feel like they have never

been listened and are suddenly given the opportunity to speak might be vulnerable to coercion.

Thus, although current research does not indicate that mental health research is significantly distressing for participants, concerns about the well-being of participants should not be entirely dismissed. Our view is that the possibility of participant discomfort or harm illuminates the importance of clear and open communication throughout the research process (see point 3 below) and of compassionate attitudes on the part of researchers (see point 4 below).

Clear communication of research purpose, process, and expectations

The importance of clear communication on behalf of researchers was mentioned by many participants. Participants emphasized that clear and accessible explanations should be offered to research participants before they consent to participate *and* throughout the research process. They should be informed about elements such as (but not limited to) the following: where interviews will take place (e.g. information about the design of buildings, the location of entrances, the presence of elevators) who they will meet or cross paths with in the process (e.g. researchers, research assistants, receptionists, other participants) and what implications their answers will have (e.g. whether or not they will impact their level of care, members of their community, or the design of a new program). Researchers are responsible for disclosing this information in ways that each participant can understand.

As Augustina specified, this might require that researchers plan more time to answer questions and build rapport with each participant. This individualized approach, however, is necessary for participants to be fully informed. When researchers fail to clearly communicate key aspects of the research process, participants may feel confused or intimated, as Jiaying, Mélodie, and Marie reported to different degrees. A large body of literature indicates that overly technical or legalistic explanations are confusing and burdensome for research participants (Beauchamp and Childress 2013). Consent forms, for example, can be extremely confusing when they are written with expert research ethics boards (rather than the participants themselves) in mind. Individuals who experience limitations understanding written text and/or aural/oral communication, for example, may be hindered by the overwhelmingly written and/or aural/oral structure of qualitative research (Dee-Price et al. 2020).

In truth, access barriers can arise at every step of the research process. The rhetorical context of research might introduce new barriers or make salient pre-existing access barriers.

This challenge requires that researchers remain actively aware of their own communication strategies throughout the research project. Creating accessibility is not a 'one-stop fix'. Instead, it requires that we "open as many different channels of communication as possible, in hopes that at least one will be accessible enough" (Price 2011, 89). Communicating information to research participants should not be perceived as a simple fix, but rather as a dynamic process adapted to each person's emerging needs (Sankary and Ford 2019; Cascio, Weiss, and Racine 2020).

Distinction between 'clinical' and humane/compassionate attitudes of researchers

The distinction between compassionate and cold (or "clinical") researcher approaches was frequently mentioned by participants. Regarding the latter, Judy, for example, evocatively spoke of feeling like she was behind a "glass wall" in the psychiatric ward. Researchers, she explained, should do everything they can to avoid making participants feel this way. Similarly, Angeline described how a "cold" and "clinical" attitude makes participants feel isolated and observed like "guinea pigs". When participants share their life story, feeling like they are being "poked and prodded" as objects of analysis by impersonal researchers is particularly harmful.

In contrast with this "clinical" approach, participants described how much they appreciated researchers who were compassionate, humane and respectful. (Angeline, Sylviane, Mélodie, Augustina, Marie-Anne, Pénélope, Judy). They emphasized the importance of listening carefully to participants, offering validation, treating participants as equals, refraining from discriminatory judgements and labels, creating an atmosphere of reciprocity, and actively working to make participants comfortable. As Jiaying and Daniele specified, supporting participants during and after the research process is not necessarily overbearing. It can be a thoughtful and much-needed gesture. To ensure that participants are comfortable, many emphasized the importance of checking in with participants at many stages in the research process and of explicitly asking them about their needs and preferences, (Judy, Nicole, Angeline). As Judy explained, there is often a taboo around discussing access needs; oftentimes, "if nobody asks you [what you are comfortable with], then you won't say it." These types of discussions, however, are crucial to ethical research practice.

Overall, the participants' observations about researcher attitudes clearly demonstrate that they do not want to be 'objectified' by clinical discourses that ignore the lived complexity of their experiences (Russo & Beresford 2015; Slatman 2014a, 2014b; Carel 2016; Lajoie 2019). By eliding participants' knowledge of their own needs and capacities, researchers foreclose the

possibility of creating more emancipatory research agendas (Fisher and Freshwater 2014). Notably, the participants' emphasis on open-ended and collaborative research structures is at the heart of research models seeking to empower research participants (Hasan and Musleh 2017; Corrigan 2002), especially through the use of frameworks such as person-oriented research ethics (Cascio and Racine 2018).

Epistemic deficits, stigma, and prejudice for individuals living with mental illness

Participants highlighted the isolation, marginalization, and stigma (including self-stigma) experienced by individuals living with mental illness (Marie-Anne, Pénélope, Sylviane). They described how people living with mental illness face prejudices and are sometimes perceived as a "nuisance" for society. Pénélope explained that these kinds of prejudices may impose limitations on the interactions that researchers can have with participants. As she explained, discriminatory attitudes creates obvious barriers for full participation. Pénélope's claim is compatible with Danielle's observation that individuals who are socially isolated and do not typically have positive social interactions due to discrimination might not participate in research studies. As a result, the voices of these individuals often remain unheard.

The harmful effects of epistemic injustice and prejudices are well documented (Corrigan 2004; Carel and Kidd 2014; Kidd and Carel 2017). Popular beliefs, social attitudes, and scientific and mass media discourses around mental illness can all contribute to marginalize individuals living with mental illness, particularly as their identities intersect with other markers of difference (e.g. race, class, gender, sexuality, disability) or their membership in stigmatized groups (e.g. forensic psychiatric patients) (Wong et al. 2017; West, Yanos, and Mulay 2014; Collins, von Unger, and Armbrister 2008). While our research did not explicitly study the impact of identify markers in the context of mental health research, this topic warrants further consideration. Overall, the epistemic deficits experienced by individuals living with mental illness are opposed to the aims of ethical research (Emanuel, Wendler, and Grady 2000).

Conclusion

Our aim in this study was to examine the perspectives on mental health research of research participation and mental health advocates. Based on our findings, we aimed to develop some recommendations for ethical research practice. We found that participation in mental health research is often viewed as a meaningful and valuable experience by participants themselves. Research participation can be beneficial to one's personal development and

self-understanding, foster a sense of involvement in society, and contribute to break systemic barriers between the development of academic discourse and marginalized knowledges. Of course, these findings do not waive the ethical responsibility of researchers to protect participants from potential harm and distress. However, ethical standards and research practices should be informed by data reflecting the actual experiences and perspectives of participants themselves.

Acknowledgements

We thank our participants for their willingness to share their experiences with us and help make us better researchers. A warm thank you, also, to the members of the Pragmatic Health Ethics Research Unit for feedback on earlier drafts of this paper.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the Canadian Institutes of Health Research under Grant 9798; and the Fonds de recheche du Québec under Grant #30998.

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