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PERSONAL NARRATIVE

Research Imitates Life: Researching Within Your Lived Experience[☆]

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ABSTRACT

This personal narrative article seeks to bring awareness to and provide an overview of the various aspects that come with being a lived experience researcher including the host of benefits and challenges that come with conducting research within one's own area of lived experience. Throughout this narrative, we (Bethany Donaghy, an autistic person, and Delane Linkiewich a person living with chronic pain) share our perspectives on what it is like to be lived experience researchers. Our narratives discuss how the many identities we hold both improve the impact and relevance of our research while also posing challenges for us like the additional responsibilities we hold and the reflections we have to make. Most importantly, we present several recommendations to all researchers on how to promote inclusive spaces and increase respect and appreciation for the expertise that people with lived experience hold. This piece outlines critical considerations of what may be considered as best practice for future inclusive research and we encourage researchers to actively consider embedding these recommendations within their own working practice.

Keywords: Lived experience, Chronic pain, Autism, Research practice, Inclusivity, Patient engagement

1. Setting the scene: Introduction

The current research landscape is pushing for the recognition and inclusion of those with lived experience. Doing so allows the voices of those who have gained direct knowledge and skills through their own experiences to be emphasized and reflected within the work we do.^{1,2} Typically this lived experience is discussed in terms of the participants whose data is gathered, or those who are engaged throughout the research process.³⁻⁵ Yet the lived experience of researchers themselves is often overlooked, with our brief literature search supporting this having found little discussion of the latter.

We all have different human experiences that inevitably influence our work, but what happens if our lived experience is directly tied to the research we

are doing? Through our conversations around this question and by considering how our lived experience both helps us to be more mindful and increases the impact of our research, this narrative came to fruition. We seek to bring the aforementioned question to life in this narrative piece by discussing our own experiences of being lived experience researchers through the lens of autism and chronic pain. Whilst we specifically speak about our own lived experience of a diagnosis, we encourage readers to think more broadly about lived experience beyond diagnoses.

2. What is with all the hats?: Inextricable identities

As researchers we juggle many hats; as doctoral students we work to establish ourselves as professionals,

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be public facing figures engaging with our participants and communities of interest, whilst trying to be functioning human beings who maintain mental wellbeing. However, some, including us, possess an additional hat encompassing lived experience in the fields we research. To contextualize our lived experience and provide positionality,⁶ Delane Linkiewicz is a young adult who has lived with chronic pain since early adolescence (Canada) and Bethany Donaghy is an autistic young adult who was diagnosed in early adulthood (United Kingdom (UK)); both are advocates in their respective communities. When discussing our experiences, we are mindful that we both identify as cisgender women and reside in Western countries.

We never relinquish our hats as our lived experiences are always with us. One hat cannot be worn without the other; they all encapsulate parts of our identities that exist both within and outside of academia. There are benefits and challenges when your research mirrors your lived experience, but it also provides an understanding of ways we can all work to create an inclusive and accessible environment for our participants and fellow lived experience researchers. However, an inability to remove hats presents an array of differing factors we address daily from an academic, interpersonal, and emotional perspective which we will discuss throughout this narrative piece.

3. A Balancing act: Our responsibilities

Our contributions to the research field do not stop at typical knowledge translation (e.g., publications, presentations) - as lived experience researchers we often hold a much larger responsibility, and we see two main ways that this can be represented: thrust upon us or welcomed.

Often, we are invited to events as representatives of our respective lived experience community, trainee community, or sometimes both. Thus, finding the perfect balance between representing our lived experience community whilst maintaining professionalism as a trainee becomes a struggle. We often interact with people more established in their career and while we want to maintain professionalism and grow our academic network, we sometimes feel the additional urge to correct or disagree with the more esteemed person's perspective of what is true for our community. For example, many presume that autistic people do not have empathy, and for those with chronic pain who work, that their pain must "not be

that bad", but these assumptions are not the case. Balancing these responsibilities that can be thrust upon us result in a demanding game of tug-o-war consequential to our competing identities.

Additionally, it can be a welcomed responsibility to advocate for, and teach others about engaging people with lived experience in research. Whilst the frequency of working with people with lived experience in research has grown in the past 20 years, there is still a need of knowing when, how, and why to do so.⁷ We often feel a responsibility to share this understanding and commitment with others as we know the impact that partnering with people with lived experience can make. A notable part of this is advocating for knowledge translation and mobilization because we know the impact and benefit the research will have on the communities we are a part of. For example, in our combined experiences we have authored publications, done research and advocacy presentations, sat on committees, partnered on research teams, and been involved in forming inclusive environments, all to further educate others. We even incorporate these methods into our own research as we both include patient and community engagement within our work. Whether responsibilities are thrust upon us or welcomed, the need to advocate for our communities and their needs is always our priority.

4. Taking a look in the mirror: Bias and lived experience

All researchers should be cognizant of bias, yet lived experience researchers should be extra mindful. Being cognizant of this bias is one reason why we engage other people with lived experience in our work. We come from different countries, so engaging people with lived experience looks somewhat different in both places. In Canada, people with lived experience are engaged as members of the research team in efforts deemed "patient-oriented research" and "patient engagement" (CIHR)⁸ and in the UK, PPI panels allow those with lived experience to have their voices heard throughout study design, analysis, and dissemination (NIHR).⁹

With that said, we have both encountered the question: "If you have lived experience, why do you need a research partner with lived experience?" Our response ties into the many hats we wear and our responsibilities because we often educate people that lived experiences look different even for those with similar experiences. We are only one voice and diverse perspectives are needed to ensure the research

is as relevant and impactful for as many people as possible. Additionally, we are aware of the privilege that we hold, like the fact that we are both white and have access to education, money, and resources, for example. The communities our research focuses on do not always reflect these sole characteristics, so it is important to include partners who represent the multitude of voices within our communities. Thus, it is important to notice own biases by constantly reflecting upon our decisions and actions, and seeking guidance from our supervisors and colleagues to ensure our work is rigorous and limited in our biases.

5. Two sides of the same coin: Differing emotional responses

As lived experience researchers, our identities are visible; we are stripped bare of armor as we are vocal about having lived experiences and each have differing emotional responses to the vulnerability this lack of armor presents.

Bethany Donaghy's field of research often demonstrates two polarizing attitudes towards autism: one that perpetuates "deficit" based views of autism, and another that reflects neurodiversity-affirming approaches of mere differences amongst neurotypes. Most researchers that Bethany Donaghy engage with either take a neurodiversity-affirming approach and/or are neurodivergent themselves leading to the creation of supportive environments where difficulties can be openly expressed and addressed. This selective engagement is intentional as, despite these positive experiences, there continues to be "deficit" based views amongst the literature, conferences, and day-to-day conversations with which Bethany Donaghy engages. This becomes increasingly exhausting and takes an emotional toll as it can be difficult to understand how, despite the best efforts of autistic advocates, these perceptions continue to prevail. An additional toll of Bethany Donaghy's is evaluating individuals' intent behind autism research (i.e. is the research neurodiversity-affirming?). Thus, she often withdraws from collaborations, despite knowing she can contribute, as the emotional toll is too much if perceptions about autism do not align.

Interestingly, Delane Linkiewich's experiences have been somewhat different. While not perfect, in recent years, Canada has become a leader in embracing the voices of people with pain: Health Canada established the Canadian Pain Task Force and people with pain sat on the steering committee; the Chronic Pain Network, a national research network, has made waves

in championing patient engagement; Pain Canada, a national action network, works closely with people with pain to increase awareness and collaborations across Canada. For the most part, Delane Linkiewich has felt positive emotions in response to the acceptance and welcoming of lived experience in her field. With that said, more work is needed to increase this acceptance.

It is interesting how some research fields have become more widely inclusive compared to others and begs the question: What is the missing piece of the puzzle for a research field to respect and listen to the lived experience voice?

6. Intertwining of experience and exploration: How lived experience impacts the research process

As lived experience researchers, we have seen how embracing and integrating our lived experiences have impacted the entire research process (i.e. this context is provided as Bethany Donaghy is an autistic researcher working with the autistic population, and Delane Linkiewich is a researcher with pediatric chronic pain experience working with pediatric chronic pain populations). We have a unique insight into important issues and gaps that our communities are facing; thus, we can use our knowledge and experiences to focus our research on things that are important to the community. For example, because of the loneliness that adolescents with chronic pain experience, which mirrors Delane Linkiewich and patient partners' experiences, Delane Linkiewich's research focuses on peer support for adolescents with chronic pain. Bethany Donaghy uses her own experiences as an autistic person and those of her Patient and Public Involvement panels (PPI) to collectively think about the adjustments autistic individuals may need to best engage with research.

Additionally, people with lived experience can play an essential role in the analysis process as they can see the results through a lived experience lens. Analytic engagement can include helping with the inclusive design of lab-based quantitative studies or theme development in qualitative research. Furthermore, we reflexively engage with the data, analysis, and interpretative process through a lived experience researcher lens as our perspectives help to situate and provide a real-world perspective about the impacts of study findings. Ultimately, our own and others' lived experiences help to renew and bring life to the research process, making research more impactful.

7. Let's turn the wheel: Our calls to action

There are ways we can all improve and embrace the continual learning experience of engagement, regardless of if you are a lived experience researcher. In writing this narrative, we felt it was key to provide recommendations for how people can contribute to moving lived experience engagement forward; as such, below we share our calls to action.

7.1. Facilitating environments that allow choice in full disclosure

People may feel the need to hide their lived experience as aspects of society and academia are not always accepting of what this experience encapsulates. We recognize it is not always safe for everyone to be open about their experiences with unsafe places breeding notions of judgment and negative experiences of individuals' exploiting this authenticity, which continue to perpetuate this valid concern. To best address this, a cultural change of understanding, acceptance, and openness to lived experience is needed by creating safe environments for lived experience researchers to flourish and feel confident in how they identify. An exemplar way of doing this may be to speak to people with lived experience and learn how to better support them, or speak to your organization's Equity, Diversity, and Inclusion team to learn more about these topics. Additionally, connecting with people who are open to or are actively supporting people with lived experience, including lived experience researchers, can help to strengthen the community of people who embrace lived experience.

7.2. Do not tokenize experience

Instead of merely integrating lived experience in your research, take time to understand what this experience means to the community. Often those who engage in research have had experiences which make them recognize and actively want to change things for their community; be sensitive to this, appreciate their vulnerability in sharing and see the value in their words. While it is important to include people with lived experience in research, it is equally important not to include them just to "tick a box" - this would be a tokenistic effort. Instead, speak to people, listen to lived experience, ask questions: learn to meaningfully engage and embrace lived experience because you see the value in doing so.

7.3. Seek out other perspectives

Engage others with lived experience as partners in research so that lived experience researchers are not the only ones bringing lived experience to the table. Whether this is done more formally through patient partnerships or more informally through discussions in the community or through your networks, the more perspectives you can seek out, the more impactful your research can be.

7.4. Check your bias

All researchers are encouraged to be aware of their subjectivity and bias, especially lived experience researchers. We suggest that everyone engages in reflective practices and seeks out supervision or consultation with others in your networks. During the latter, have respectful and frank discussions about where ideas relating to research questions, data analysis, and interpretation have come from to ensure that a researcher's lived experience is augmented and not overshadowing the work. Further, include positionality statements within your work (e.g., publications, presentations) to be transparent about your "multiple hats" and acknowledge the intersectionality that exists within it.

7.5. Be kind

Plenty of people may obtain lived experience as time goes on, for example, through a new, or newly recognized, diagnosis. Be kind to how someone's identity may shift from someone without a title for their lived experience, to someone with. Similarly, if someone discloses a diagnosis to you, appreciate what they have told you and their vulnerability in sharing instead of contributing to the stigma. Be open to lived experience researchers and the expertise they bring, and be open-minded when these matters of disclosure differ to your initial thoughts. Ultimately, the effort to try, even though you may not always get it right, is what matters most.

8. Conclusion

Lived experience is vital to research - it drives the work we do through inclusion, recognition, and accessibility; yet for too long we have overlooked the impact this has on those who research within their own lived experience. The recommendations we present are meant to be dynamic just like that of experiences; every day provides opportunities for these

experiences to be reformed and thus the suggestions provided should reflect this. We encourage people to understand more about lived experience and get comfortable with being uncomfortable by simply asking the questions that matter - be open-minded to the effects this stream of work has regardless of your position on it.

Conflict of interest

The authors declare no conflict of interest.

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