The View From the Inside: Positionality and Insider Research

Danielle Berkovic1, Darshini Ayton1, Andrew M. Briggs2, and Ilana N. Ackerman1

Qualitative research has traditionally prioritized consumer and community engagement (Attree et al., 2011; Sarrami-Foroushani et al., 2014). Similarly, clinical research is placing increasing value on consumer and community engagement, commonly labeled as “patient and public involvement” (PPI; Boivin et al., 2018; Lalani et al., 2019). PPI aims to enhance the quality, acceptability, and relevance of research (and priority setting in research) to ensure that issues of importance to patients, their families, and the broader public are addressed (Brett et al., 2014). It has been acknowledged that PPI can improve the quality of health-care delivery and patient outcomes (Boaz et al., 2016). However, despite the demonstrated positive impacts of PPI, many research projects are still conceptualized and undertaken with relatively minimal input from those with lived experience of the condition (Vayena et al., 2016). Most commonly, PPI is sought at the conceptualization phase of research where topics of prioritization are identified; yet, there may be minimal input after this stage (Manaf et al., 2018). These limitations have motivated patient-led research, where an individual with lived experience of a health condition is taught research-related skills to examine the topic of interest from conceptualization through to dissemination of outcomes (Grant et al., 2019; Streuli & Vayena, 2015).

The research program that I conceptualized, developed, and am currently undertaking with the support of my supervisory team was borne out of my lived experience as a young adult with inflammatory arthritis. The concept where I am the researcher is known as “insider research.” Within the insider research paradigm, I, the researcher, relate to my participants’ identity and language through personal arthritis-attributable experience (Greene, 2014). Insider research, which occurs through a process of positionality, involves intentionally aligning one’s self-interests with one’s research (Jacobson & Mustafa, 2019). There are advantages and disadvantages of conducting insider research in the qualitative research sphere. Some advantages of an insider position include (1) facilitating a nuanced perspective that builds credibility with participants, (2) promoting an equalized relationship between the researcher and participants, and (3) building rapport between the researcher and participants. In contrast, potential disadvantages can include compromised researcher objectivity and professionalism and participant misunderstanding of a researcher’s capacity to provide health advice (Chavez, 2008).

As a young adult with inflammatory arthritis, I am particularly interested in the impacts of musculoskeletal conditions on working-age populations. There is a large body of research conducted with pediatric populations with arthritis (Cartwright et al., 2015; Cohen et al., 2017; Soriano LeBovidge et al., 2003) as well as with older adults with arthritis (Focht et al., 2017; Havens et al., 2017; Song et al., 2006). However, there is a paucity of research dedicated to working-age populations. This is particularly concerning, given that in Canada, over 50% of the population with arthritis are aged under 65 years (Statistics Canada, 2019), and similarly in Australia, 50% of the population with arthritis are of working age (Australian Bureau of Statistics, 2018). A large number of Australians are forced into early retirement each year, and females retiring early have been found to accumulate, on average, 83% less in retirement savings than their healthy peers (Schofield et al., 2013). Based on my lived experience and personal interests, and in recognition of the limited research undertaken to date, our research program seeks to explore the broader impacts of arthritis (beyond joint pain and stiffness) with respect to work implications and

1 School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia
2 School of Physiotherapy and Exercise Science, Curtin University, Perth, Australia

Corresponding Author: Danielle Berkovic, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia. Email: danielle.berkovic@monash.edu
financial stresses. This research is also supported by a consumer organization with similarly aligned interests.

This research program is a qualitative-dominant mixed-methods project. The first research aim was to explore the physical, psychosocial, and financial impacts of living with arthritis. This aim was examined through 21 semistructured interviews with female and male participants who had a range of arthritis conditions. Prior to designing the interview guide, I recognized that I needed to reflect on my own experiences with arthritis, to ensure that the questions used were open and not biased by my own experiences, or expectations of potential participant narratives. To achieve this, and with guidance from my supervisory team, I undertook a bracketing exercise. Bracketing is a method used in qualitative research to identify, examine, and mitigate researcher preconceptions that may influence the research process (Tufford & Newman, 2010). Bracketing works by explicitly noting one’s own beliefs and interaction with the research topic, in an attempt to remain impartial throughout the research process. Bracketing promotes methodological rigor and trustworthiness in the conclusions drawn from qualitative research, which is pivotal in the context of insider research.

I began my bracketing exercise by preparing brief points about my own arthritis journey. I was diagnosed with psoriatic arthritis (a type of inflammatory arthritis) nearly 8 years ago. I take disease-modifying antirheumatic medications that control my disease activity, and I have an excellent health-care team. I have supportive family and work environments, where I am surrounded by individuals with high health literacy and empathy. Reflecting on my personal arthritis-related experiences—at the very beginning of my bracketing exercise—unexpectedly drew my attention to how fortunate I am in my experiences. It was, therefore, important for me to be aware that my research participants might have vastly different circumstances. To assist the data collection process, I developed some guidelines to adhere to during my interviews:

1. It is essential that I do not assume to understand the lived experience of my participants. It is important to remember that individuals have unique biological determinants and clinical profiles, are raised in different environments, and have varied psychosocial experiences.

2. It is imperative to remain impartial during the interview process. It is not my role as the researcher to view my participants’ experiences through my own lens.

3. In maintaining impartiality, it is important to collect rigorous data via semistructured and probing questions rather than to engage in general conversation that is based on shared or divergent experiences. Some emotional investment is perhaps natural, but to maintain awareness around it is vital.

4. It is important for me to recognize my privilege with regard to the level of support that I receive, including but not limited to access to the private health-care system in urban Australia. My participants may not have access to the same resources.

5. It is also crucial to maintain my role as the researcher. I am not a medical professional, and I am not qualified to provide my participants with health-care advice based on my own experiences.

I continued this bracketing exercise through each stage of the research project to acknowledge, and mitigate, my own biases. I had to ensure that my research aim was exploratory, as opposed to confirmatory, with clear and robust direction. Further, I wrote a reminder on my interview guide, next to my probing questions, to ask participants to explain or expand on concepts that may not be clear to individuals without arthritis. In the data analysis stage, I highlighted the importance of giving adequate voice to my participants through a process of open, axial, and thematic coding, with independent verification from my supervisory team to ensure that derived themes were representative of the data. Further, my supervisory team who are experienced in arthritis-related research reviewed my processes to ensure that our research was clinically relevant and methodologically sound. Overall, the bracketing exercise redirected my research program away from being influenced by my experiences to focusing on data generated by other young adults living with arthritis.

However, when reflecting on interviews I conducted with some younger participants, I did notice that my perspective shifted. I found myself speaking with a compassionate tone, which helped build rapport but also led to a more conversational approach than structured data collection:

Participant: Actually, I tore my meniscus in January, so I’ve been hobbling around a bit anyway.

Interviewer: And was that unrelated to the arthritis? Was it a gym thing, or...

Participant: That was a sport-related injury, not related to my arthritis at all.

Interviewer: Ouch, I came close to tearing my meniscus, it wasn’t quite a tear and I was in so much pain so I could only imagine.

Participant: Yeah, it was not fun.

Interviewer: It’s so frustrating, there’s just no blood flow there and it doesn’t heal.

Participant: No, no, the worst. Yep, I know!

Being an “insider researcher” has taught me several valuable lessons. Most interestingly, I observed that some of my participants became tense and closed off to answering questions when I revealed that I too had arthritis. On reflection, our shared experience may have diminished their perceived neutrality of the interview, potentially creating distrust. Other participants were happy to find out that I could relate to their experiences. In return, they answered the interview questions in detail and trusted me with their story. Contemplating these experiences, I consider there is no right or wrong way to position oneself when undertaking insider research, as long as one always maintains respect and ensures that ethical principles and
objectivity underpin the research. In addition to the lessons learned, there are aspects of insider research which warrant future consideration and perhaps recommendations to guide the field. Is positionality a type of competing interest that should be declared uniformly to participants and/or to ethics committees? Are extra efforts needed to promote objectivity and rigor? In my situation, this was achieved by pilot testing my interview schedule and consulting regularly with colleagues who brought an “outsider” perspective to interpreting the emerging themes.

Overall, we have much to gain from insider research. As health research increasingly supports person-centered care and qualitative approaches, it is timely for patients to initiate and drive research that they prioritize based on their unique lived experiences. The perceived value of insider research is also apparent; through this process, I have spoken to many young adults with arthritis who have expressed excitement that their narratives are being highlighted for the first time. This type of inclusive research can only promote positive outcomes for people with health conditions.

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