

The Merits and Pitfalls of Participatory Action Research: Navigating Tokenism and Inclusion with Lived Experience Members

Abstract

This paper explores the merits and pitfalls of involving people with lived experience of a phenomenon of interest (e.g., poverty, hunger, housing deprivation) in Participatory Action Research (PAR). As a researcher who has conducted PAR and community-based research for several years, the author has gained deep insight into the value of having lived experience members in PAR research projects, but also has developed a familiarity with the challenges attendant to such work. This paper, using autoethnographic methods, provides an overview of PAR, including its purposes and objectives. Aiming to move past tokenistic inclusion, the author will then outline how PAR can promote genuine inclusion of all members of the research team, irrespective of their social identities, backgrounds, and/or (work, academic, organizational, or community) affiliations. Issues associated with meaningful participation, however, include various relational (e.g., issues of power), ethical (e.g., risks of participation), emotional (e.g., research triggers), economic (e.g., remunerating contributions and financially supporting participation), representational (e.g., whose perspectives are advanced), and structural barriers (e.g., time, technological connectivity, etc.) will be discussed, using concrete examples. Bringing together people that may hold disparate perspectives, community ties, worldviews, and visions associated with a research undertaking can create challenges, yet not including those who experience the phenomenon of study can create even more.

Keywords

Autoethnography; inclusion; lived experience; Participatory Action Research; policy process; tokenism

Introduction

Increasingly researchers are finding that traditional research dissemination methods are not always expedient in shaping the policy process and ineffectively grapple with the neoliberal ‘polycrisis’ (see Torkington, 2023) that confronts us globally (Sandwick et al., 2018). As such, some have adopted more participatory and action-oriented approaches to broaden the reach of their knowledge production (e.g., Ungar et al., 2015). A substantial literature base has amassed that captures the promise of conducting engaged research through a Participatory Action Research (PAR) approach, and the expected knowledge coproduction, empowerment, and democratic decision-making that burgeons from it (Mason, 2015). Research also speaks to its distinct practical, epistemological, ethical, and relational challenges (Cornish et al., 2023; Lake & Wendland, 2018).

PAR largely draws from two research methodologies, participatory research and action research, albeit each is associated with disparate ontological, epistemological, and methodological origins. Participatory research emerged in the 1970s and 1980s in the context of anti-colonial movements in the global South. This methodology aligned with researchers who sought to shake off the hierarchies of Western empiricism, and to acknowledge and embrace the epistemic privilege of subjugated groups (Cornish et al., 2023). PAR draws from Paolo Freire’s theoretical contributions of conscientization, embedded in a critically reflective practice (or praxis) that permeates all aspects of the research process, and which is assumed to lead to an emancipatory politics of social change (Cahill, 2007). Indigenous scholars also gave rise to PAR in seeking to infuse extant knowledge production with Indigenous traditions of participation and community engagement (Cornish et al., 2023). Advancements in the feminist movement too contributed to PAR, recognizing that indeed, the personal *is* political; experiences in the private domain (including expressions of exploitation, violence, and an unequal division of labour) ought not to be relegated to subsidiary import, or as domestic or familial matters alone, but should be of primary public and societal concern (Cahill, 2007). PAR thus shares synergies with feminist, post-structural, and postcolonial paradigms (Kendon et al., 2009), and espouses the ‘nothing about us without us’ motto of the disabled community (Harrison et al., 2001).

Action research, the other methodological contribution to PAR, frequently draws from Kurt Lewin’s (1997) work that seeks to move beyond research as mere description or explanation to engage a group of people in activating an iterative cycle of planning, action, and

evaluation to effect change (Streck, 2014). Between the nexus of ‘action’ and ‘research’ a group of people can test “ideas in practice as a means of improvement and as a means of increasing knowledge” (Corbett et al., 2007, p. 82). In addition to Lewin, John Collier is oft associated with the family of research strategies attendant to action research. Collier, the US Commissioner of Indian Affairs between 1933 to 1945, employed ‘research-action’ to refer to the cyclical nature of social inquiry, research that produces “action research and research action” (Corbett et al., 2007, p. 82). Although action research is participatory, it does not necessarily involve those most affected by the given problem in all dimensions of the research process (Mackenzie et al., 2012), nor does it apply a critical theoretical lens to its work (Corbett et al., 2007).

As an orientation to research not a methodology per se, PAR does not subscribe to set of methods or methodologies, but embraces the full assemblage of qualitative, quantitative, mixed methods, and arts-based approaches. Put simply, “PAR involves researchers and participants working together to examine a problematic situation or action to change it for the better” (Kindon et al., 2007, p. 1). PAR blurs the “distinction between researcher and researched” (Mackenzie et al., 2012, p. 12), and is occupied with “learning while doing” (Greenwood & Levin, 1998, p. 81). It situates all members of the team as equals, each with their own knowledges, skills, and perspectives to draw from, allowing research to be conducted with—not on—specific groups of interest (Lac & Fine, 2018).

PAR teams are committed to democratizing the research process. Rather than the investigator determining a priori what the research could and should entail, PAR opens opportunities for knowledge to emerge “from below” insofar as it “takes lived experience as the starting point for investigation, values the knowledge produced through collaboration and in action, and may contribute towards social change movements” (Cahill, 2007, p. 268). In this way, PAR gives ownership of the research to disenfranchised groups, contributes to research validity, and decolonizes the research process by dislodging traditional research canons of “who gets paid, speaks for the work, and has veto power over what goes public” (Sandwick et al., 2018, p. 477). Therefore, to truly be a PAR approach, all aspects of the research must be delineated by the team, including considerations of the research questions posed, the methods employed to examine them, and the mechanisms applied to transmit the knowledge (co)created through these processes. It involves, according to Young (2006), a transformative and empowering process in which a sense of community is developed, people educate each other,

community consciousness is raised, and knowledge is mobilized to enact organizational, community, and systemic change.

Despite the vast reservoir of research pointing to the inspirational character of PAR, Cahill (2007) detects a “mismatch” (p. 269), as do others (e.g., Hawkins, 2015; Pain & Francis, 2003), between its theoretical aspirations and its actual practice on the ground. Indeed, Sandwick et al. (2018) conclude that PAR is “no panacea” (p. 475), but is continuously confronted by ethical, political, and power-laden dilemmas. The most problematic, as Cahill (2007) notes, “are those research approaches which in the name of participation mask realities of tokenism, reinforce social hierarchies, emphasize consensus, and reproduce the dominant hegemonic agenda” (p. 269).

METHODS

Autoethnography emerged from the field of ethnography as a means to draw the researcher’s observations and experiences into the phenomenon under study (Poulos, 2021).

Adams et al. (2014) maintain that as a qualitative research method autoethnography

(1) uses a researcher’s personal experience to describe and critique cultural beliefs, practices, and experiences; (2) acknowledges and values a researcher’s relationships with others; (3) uses deep and careful self-reflection—typically referred to as “reflexivity”—to name and interrogate the intersections between self and society, the particular and the general, the personal and the political; (4) Shows people in the process of figuring out what to do, how to live, and the meaning of their struggles; (5) balances intellectual and methodological rigor, emotion, and creativity; and (6) strives for social justice and to make life better. (p. 2)

In foregrounding the experiences and emotions of the researcher, autoethnography eschews the objectivist pretensions of conventional research methods, and acknowledges the constructed nature of knowledge by harnessing “subjectivity deliberately as an epistemological resource” (Butz & Besio, 2009, p. 1662). In so doing, the researcher can engage a process of critical reflexivity, described by England (1994) as “self-critical sympathetic introspection and the self-conscious *analytical* scrutiny of the self as researcher” (p. 82; emphasis in original).

Denzin (1989) describes the ‘personal experience narrative’, or ‘narratives of the self’ in the words of Richardson (1994), as a representational form to tell stories about one’s experiences

in everyday life. Here, the researcher becomes the primary research subject, met with the same critical analysis and rigour imposed upon any other social inquiry. This paper uses autoethnography to highlight the nuances of engaging in PAR from the perspective of a researcher who has adopted this orientation to advance a robust program of research seeking to influence the policy process in their local community.

Positionality

As a feminist, cis-gender woman, mother (of three children, one with a serious congenital heart defect), and person with past lived experience of deep poverty, food insecurity, and housing instability, I understand how systemic processes coalesce to reproduce the conditions that perpetuate social inequities. Yet these experiences have also fuelled my quest for justice, with a passion that has seeped into my teaching, community activism, and research agenda. Anchoring my research and activism to meaningful knowledge creation and transformative social change, my program of research reflects a drive to address key health and social inequities (i.e., poverty, hunger, homelessness, intersectional disparities), the corollaries of which have had devastating impacts on equity deserving groups, especially Indigenous, racialized people, disabled people, women, and Lesbian, Gay, Bisexual, Transsexual, Queer, and Two-Spirit populations. This work is typically grounded in critical theoretical paradigms (e.g., critical disability studies, critical feminism, intersectionality) to explore how impoverishment, disability, oppression, and social inequities are reproduced in societal structures, systems, and social relations.

My foray into PAR began in my mid-career as an academic. While I sought from the start to build partnerships and connections within the various communities with whom I worked, I did not formally adopt PAR at the commencement of my journey as a researcher. I had heard anecdotally from others that engaged in such work that PAR, while fulfilling, was also exhausting, time consuming, and tended to be fraught, both by a dearth of resources and an overabundance of power dynamics (see Table 1 with literature on the positive attributes of PAR, the enablers of this work, and the challenges and pitfalls attendant to it). My work as a basic income activist in the London, Ontario community, where I previously lived and taught, allowed me to practice using the various principles of PAR (e.g., participatory, dialogic, democratic,

team-driven, change oriented, etc.), even while the team (involving students, colleagues, and community members) had not invoked PAR as its distinct design or methodological signature.

In my current position, I have been drawn to PAR because I began to believe that my work as an academic might have only limited influence on the policy process. The various work and familial demands on my time made my full insertion into the life of activism unmanageable. I was thus drawn to PAR believing in the power of the collective, and the possibility that working in partnership with others presented to positively effect social change. As such, I have worked with a PAR team for the last few years, comprising a group of students, community members, people with lived (and living) experience of poverty and homelessness, policymakers, health and social service providers, and educators. What follows are some of my reflections on and with PAR in my own life. Given the requisite need to protect the identity of members of the teams with whom I (have) work(ed), I will discuss incidents and experiences as broader themes to paint a composite picture of my experiences, while avoiding references to specific persons, places, or dates.

FINDINGS

An autoethnographic account of PAR

My engagement in PAR has been fulfilling, but simultaneously daunting and tumultuous. Like Lac and Fine (2018), I found I went into such work with a certain naivete about how the process would unfold and the hurdles we would encounter. The first was related to recruitment. While I had some contacts interested in participating on the PAR team, I worked with my institution's research office to make recommendations on how best to achieve maximum variation in the recruitment process. It was important that the team cut across social intersections of age, race/ethnicity, gender, sexual orientation, and socio-economic status, as well as educational, family, and employment statuses. Recruitment posters were produced and sent out through the researcher's community, academic, and personal channels. In so doing, the initial members of the team (roughly 10 to 15 participants) represented a wide variation of identities, interests, and experiences. Given the importance of having members with experience of poverty and homelessness, specific attention was paid to recruiting people that had previous encounters with financial and housing insecurity or who were presently vulnerable to these social problems. Although we were not successful in recruiting people currently living rough on the team, there

were those who had previous experiences with being deprived of housing or whose living situations were, at present, precarious. Members presented a broad swathe of identities, including disparate genders, ages, sexual orientations, ethnicities, and abilities. Given that this team had formed during the COVID-19 pandemic, meetings were held on-line at a time convenient for the majority.

The first few meetings of the PAR team were devoted to creating our teamwork protocol, an important process for building trust and establishing a co-generative space (see Van Acker et al., 2021). After introductions were made, including a request that participants talk a little about themselves and why they were drawn to the team, we devised what “Our Ways of Working Together” protocol would entail. The ideas ranged from building relationships built on respect, trust, and friendship, fostering a sense of community, as well as working collaboratively to resist the status quo and advocate for systemic change in our community. Although I gave the initial introduction, I was quick to hand over the discussion to my colleague, a doctoral research assistant hired to assist the team with its work, to signal my role as participant, not assumed leader of the group. Once the protocol was delineated, participants were asked if they agreed to the items (responding in the affirmative in the Zoom chat box). After some discussion, team members were asked to consider the purpose of the team and its key objectives. It was clear early on that poverty and homelessness, and remedies to address them, were clear areas of shared interest. The brainstorming roundtable session also led to discussions about possible projects the team could take on, involving smaller working groups of the team as suited members’ schedules, knowledges, strengths, and skillsets.

PAR meetings were held on-line, and even when the health emergency had subsided, the team had become accustomed to the convenience and accessibility of the Zoom platform and thus continued to meet virtually. This could also be seen as helpful as it may have contributed to providing a greater sense of safety to a group of initial strangers (see Adams & Moore, 2007). Ongoing consent to engage in the research was demonstrated to be, as Mason (2015) described, a fluid, contextual, and iterative process. The team experienced significant turnover over the year. Some students came and went, with spotty attendance given the shifting demands of the student in the academic school year, as did community members. The turnover was keenly felt at the beginning of our work together, possibly because some of the individuals that had gravitated to the group had appeared to have done so to advance their own personal agendas. We had several

people leave in the first year because their personal ambitions and plans for the group were not translating into the outcomes or actions they had originally envisaged. Requests were proposed, for example, for the team to write grant applications or publications that primarily highlighted the work of the organizations and/or motivations of the individuals representing or rendering them. Once it was decided by the team not to pursue these requests, these members abruptly disappeared.

Given the dynamic approach of PAR in “constantly venturing into unexplored territory and thus always revealing new challenges and risks” (Mason, 2015, p. 497), other issues that are not well represented in the literature also emerged in our joint work. Incidents of emotional trauma and physical threat are seldom discussed in the research literature, yet some researchers and team members adopting PAR can indeed “find themselves in compromising situations” that threaten their physical and/or emotional safety (Adams & Moore, 2007, p. 67). People subjected to ongoing impoverishment and homelessness recurrently experience significant trauma. The consequences of such trauma present in a multiplicity of ways, including mental health challenges and manifestations of substance use. Ways to contend with the varied displays of such inner turmoil were not always clear to the team yet took considerable time and energy. Although the team endeavoured to operate from a trauma-informed approach, the intricate nuances of applying it were decidedly murky in practice. Here, the epistemological orientation to the kind of ‘ethics of care’ Cahill (2007) described was firmly tested. Discussions on when to check in on participants were had, as were talks to process reactions to difficult conversations, potential vicarious trauma, or situations involving participant safety. Secrets shared privately or in the group could also place emotional burdens and stress on team members, depending on the nature and severity of these disclosures (see Adams & Moore, 2007).

As a researcher who engages in multiple research studies simultaneously, in addition to my tending to my responsibilities as a faculty member, instructor, mother, and partner, with the PAR team being but one, I found my time to be wholly consumed, leaving little time for reprieve, self-care, or connections to my larger social network. Having PAR members as both colleagues and friends meant that I opened myself up to ongoing conversations on text and email; the volume and intensity of which I sometimes struggled to keep up with. Invitations for coffee or ‘just to chat’ produced feelings of guilt, as I could not always respond immediately when people wanted to meet. Boundaries and vulnerabilities, as Frisby et al. (2005) document,

were also challenged. These were exposed, for example, when I as a woman had to ask another colleague to participate with me on a call with a member that might misconstrue the friendship we had fostered as being romantically motivated.

Remuneration for participating in PAR raises recurrent ethical issues. Questions linger among researchers and institutional review boards about the appropriate amount of cash incentive to recognize people's research contributions without being deemed coercive for those perpetually cash strapped. PAR team members were given financial increments of \$50 per meeting to recognize their time and contributions. Yet the form needing to be completed to obtain the cash required that participants respond to a slew of intrusive personal questions, including rendering their Social Insurance Number to comply with the directives of the Canada Revenue Agency. Issuing cheques meant additional, unhelpful work for people wary of banks or financial institutions or whose living arrangements were precarious and subject to continual change.

Navigating issues of power, privilege, and voice is not an easy or straightforward task. While on the one hand, our team has sought to promote equity in terms of speaking time and a fair division of labour, I have noticed that a few voices take up more space than others, and endeavouring to remedy the imbalance can be challenging. People who enjoy sharing their thoughts and ideas can sometimes dominate the group, and unwittingly, silence or exclude others in the process. Meanwhile, other PAR team members around the table have shied away from the spotlight and have not always been forthcoming with their suggestions and feedback or appeared reticent to take on work. Intentionally seeking to draw people out who may be reluctant to share was not always productive, as not all were comfortable with being put on the spot and/or preferred not to share their ideas in the larger group. With attrition over time, the move to a smaller PAR team (6 to 8 members) proved especially advantageous on that front, as it allowed people with various social anxieties to participate in a smaller, more intimate setting, offering a space for more equitable participation.

Akin to the oscillations in the quality and quantity of participation on the ladder of citizen participation (Arnstein, 1969), such variations were visible in our PAR endeavour. Some PAR meetings appeared to simply be used to inform team members of the status of the various projects we were undertaking (with smaller working groups of the team, and/or in collaboration with other community projects underway), whereas other meetings demonstrated a higher degree

of participant control, as team members, for example, collaboratively developed scripts for digital content we were co-producing. As we sought a consonant blend between knowledge co-creation and action mobilization and dissemination, our work typically comprised discussions on several different research studies (involving a mix of quantitative and qualitative methods), along with various activities (e.g., the creation of digital content, podcasts, videos, social media posts, petitions, infographics, etc.) the team was advancing. Some of these projects were funded through grants the team had been awarded, others were fuelled strictly from the volunteer time and dedication of the team.

Tensions around power permeated the group, albeit often in hazy, indistinct ways. I sought to refrain from wearing my hats as educator and researcher to actively minimize power differentials. Yet, relinquishing these roles made it more challenging to ask others to critically reflect on and question the ideologies, narratives, and myths within the dominant social milieu, some of which team members also espoused. Like Smith et al.'s (2010) experiences using PAR, one of the most difficult issues for me to navigate was that the people around the table, although holding significant lived and living experiences of poverty and homelessness, and thus having a fulsome understanding of the systemic barriers associated with these social problems, had internalized many of the neoliberal discourses pervasive in society. After years of socialization, these had permeated into the collective psyche of team members, many of whom had not had an opportunity to reflect critically on them. I was not always sure of the most appropriate way to challenge these views without invoking my privilege as a researcher to educate the group on the apparent contradictions inherent within the global capitalist system. I thus found that I was reluctant to share the valuable findings I had discovered over the years for fear of alienating group members. Taking a backseat in discussions made it appear that I had little knowledge to contribute, despite engaging in research in this area for over two decades. Yet I found that if I captured too much airtime sharing my own knowledge, I could silence others who had too often not been heard.

Poverty and homelessness not only exact a significant emotional, social, mental, and physical toll on people, they also demand their time, energy, and attention. Participating in a research study can seem rather gratuitous or trivial when endeavouring to find shelter or one's next meal. Those with living experience of such profound hardship therefore have little time to engage in research that might or might not improve their circumstances and wellbeing in an

uncertain neoliberal (and thus increasingly precarious, unequal, and climate disruption-prone) future. While researchers have sought to embrace people with lived and living experience of mental illness, homelessness, and poverty in their PAR work, the lack of time necessary to include them in all aspects of the research endeavour risks tokenistic involvement. Indeed, we found that recruiting people with direct experience of living rough seemed a near impossible task, as the demands imposed by mere survival are heavy and expose people to ongoing and repeated crisis events that are all consuming (see McCullough & Havens, 2012).

In exploring ways to end poverty and homelessness, the PAR team employed qualitative research methods to collect the stories and perspectives of those systemically positioned for these social problems. People encountering significant trauma, stress, and violence often acquire health conditions, and as noted, are repeatedly subjected to crisis situations. Some individuals we encountered were in the process of being sent to the hospital (or another health or psychiatric facility) or were being evicted from their current shelter or accommodation arrangements. Others lacked broadband internet access or a cell phone, while still others were involved in grueling custody battles, were fleeing violence or went missing since the time we made initial contact.

While having access to a health crisis line (a standard inclusion in research ethics protocols involving populations deprived of housing and or in financial hardship) was on hand, endeavouring to have some PAR team members, who were also exposed to these social problems, participate in the research as peer research associates raised issues. While many members thrived in the context of taking action to resist the injustices they observed in their life and in the lives of others, a few felt the traumas of these adverse experiences were just too fresh and needed to be adequately processed (with time and support). Having a variety of research activities underway that people could become involved in allowed team members choice to determine which projects, and in what capacities, they wished to be involved.

Some community-based research projects I have engaged in, albeit not all utilizing PAR, have opted for ‘lived experience panels’ as a means to tap into the perspectives of those most affected by poverty and homelessness, but without necessarily having them participate in all aspects of the research. Some of these panels have been helpful in anchoring their research to lived and embodied realities. Others, however, appear merely tokenistic. Revealing a thin veneer of participation, some lived experience panels afford people the opportunity to share their unique perspectives and ideas but do not equip them with the power to make decisions or to be included

in ways they wish to be. These, in my view, could be more damaging than if the team members had not been involved at all, as they epitomize and promote exclusion.

Seeking to promote genuine inclusion of PAR team members requires ongoing critical reflective practice, time, energy, and dedication. Here, working to develop praxis – an iterative process of reflection and action – is key (Freire, 2017). Having time and space in PAR meetings to reflect on our activities, processes, and actions allows us to pay attention to the dynamics and tensions that underlie our shared work. Critical reflective practice also requires that we identify and process our thoughts and emotions, as well as the discourses we seek to advance, clarify, or dislodge. For example, seeing anger and rage not as emotions that should be muted or quickly dissolved, but as responses that can be harnessed for passionate action. It is these times, when the team is reflecting on its processes, and on our own beliefs, assumptions, and biases, that we are drawn closer together, engendering a clearer resolve to collectively effect change.

Conclusion

Bringing together people that may hold disparate perspectives, community ties, worldviews, and visions associated with a research undertaking can create challenges, yet not including those who experience the phenomenon of study can create even more. Engaging in applied research that does not consider the perspectives of those most affected by a phenomenon is not only exclusionary, but it may also lack validity (on the latter, see Schneider, 2012). Although I have encountered numerous issues, and invariably will continue to do so in the future, in doing PAR work, I anchor my research to the possibilities envisioned by the collective, working with hope (Freire, 2021) with my colleagues in PAR, to enact an alternative, and more transformative, future.

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Positive Attributes of PAR	Sources
Participatory and democratic decision-making	Frisby et al. (2005); Smith et al. (2010)
Builds confidence and self-efficacy of members	Rosenthal & Khalil (2010)
Meaningful and rewarding	Dawson & Sinwell (2012); Smith et al. (2010)
Harnesses Freirean emancipatory pedagogy	Smith et al. (2010)
Applied research and activism to solve real-life problems	Mackenzie et al. (2012)
Flexible, emergent, and dynamic	Mackenzie et al. (2012); Smith et al. (2010)
Wider access to information and networking	Mackenzie et al. (2012)
Learning while doing, develop new skills and expertise	Mackenzie et al. (2012)
Greater validity and credibility of research informed by lived experience of those involved	Frisby et al. (2005); Thurber et al. (2018)
Enablers of PAR	
Trust in relationships	Smith et al. (2010)
Self-reflection and reflexivity – navigating assumptions, insider/outsider, and privilege/penalty positionalities	Cahill (2007); Cornish et al. (2023); Mackenzie et al. (2012); Smith et al. (2010)
Power sharing (researcher relinquishes control and members take up control)	Rosenthal & Khalil (2010)
Openness, transparency, and interpersonal vulnerability	Smith et al. (2010)
Clarity of roles and responsibilities	Mackenzie et al. (2012)
Challenges and pitfalls	
Differing motivations and objectives	Smith et al. (2010)
Takes time and resources, including personal investments	Mackenzie et al. (2012)
Misunderstood by institutional ethics boards	

Members espouse stereotypes and narratives within dominant society	Smith et al. (2010)
Revolving door of students and/or members	Smith et al. (2010)
Navigating ownership	Smith et al. (2010)
Tricky gendered relationships and safety concerns	Adams and Moore (2007)
Challenging ethical considerations	Frisby et al. (2005)
Risk of co-optation	Cornish et al. (2023)