SOCIAL WORK'S COMMITMENT TO CHANGE: PARTICIPATORY ACTION RESEARCH AS PRACTICE WITH MARGINALISED GROUPS IN THE CARIBBEAN

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Abstract

This article presents an argument for participatory action research (PAR) as a pertinent methodology for Caribbean social work researchers. The synergies and capacities of both PAR and social work practice for engaging marginalised populations are discussed, with specific reference to their histories of working with disenfranchised groups. Reflecting on collaborative engagement across two PAR studies, the ways in which PAR functioned as social work practice are discussed. Four mechanisms used in the PAR studies to foster engagement, namely reflective practice, creating dialogical spaces, critical reflection, and research dissemination, are examined by considering how they support crucial processes for both research participants and research audiences. A discussion on epistemology and ethics as it relates to engagement in PAR is also included. The social work researcher engaged in PAR is discussed as a practitioner engaged in a change process intervening across the micro / macro divide to gather data and translate knowledge into action.

Keywords: social work research, PAR, social work practice, marginalized groups

Social Work's Commitment to Change: Participatory Action Research as Practice with Marginalised Groups in the Caribbean

Reflecting on social work knowledge, values and skills, Shaw and Holland (2015) asserts that " 'knowing' and 'doing', 'research and practice' are not two wholly distinct areas that need mechanisms to connect them, but are to a significant degree part and parcel of one another" (p. 16). There are tensions around how to distinguish social work as a science in the research literature, however, there is a measure of agreement on the characteristics of what makes social work research a distinctive form of investigation. Brekke (2014), underlining the urgency to establish a definition of social work science, suggests that research must mirror social work practice as an applied discipline that is foremost, attentive to improving lives. The notion that as an applied discipline, whether using qualitative or quantitative methods, social work research should be above all pragmatic, is echoed throughout the literature (Anastas, 2014; Thyer, 2010). It has been argued that social work research should reflect "debates about the nature and purposes of social work itself" (Parton & Kirk, 2010, p. 35) and that researchers "should focus our science mostly on the poor, marginalized, disenfranchised, and vulnerable" (Howard & Garland, 2015, p. 194).

Drawing from social constructionism and critical paradigms, participatory action research (PAR) has an evident alignment with social work practice. PAR is a particularly pertinent methodology for social work researchers because of its unique "political and methodological intentions" (Kemmis & McTaggart, 2007, p. 559) It aligns with social work's core commitments to fostering collaborative relationships, anti-oppressive practices, and social change. Blum et al. (2010) contend that "the values and ethics of social work fit well with the principles of PAR in the pursuit of justice and social change [because it aims] at improving conditions for those who were seen as disempowered or excluded from the mainstream in some way" (p. 451)

In this article, I present an argument for PAR as a pertinent methodology for Caribbean social work research with marginalized populations. I reflect on how collaborative engagement with participants across two PAR studies functioned to translate research practice into social work practice. I do not endeavour to report study findings, but rather to discuss core mechanisms used in PAR to foster research engagement. In so doing, I make a case for how reflective practice, creating dialogic spaces, critical reflection, and research dissemination in PAR as social work practice are crucial processes for both research participants and research audiences.

Distinguishing features of PAR

In *Participatory Action Research: Theory and Methods for Engaged Inquiry*, Chevalier and Buckles (2019), using the analogy of mythic characters known as tricksters who flout conventional behaviour, describes PAR as follows: "Many have heard about the creature, they know it exists, but no one is entirely sure what it looks like or how much trickery is needed to create and sustain it as a single entity" (p.11). PAR is an umbrella term, which covers a variety of participatory approaches to action-oriented research. It can be defined simply as a process in which researchers and participants collaborate to investigate a challenging situation, and then implement change toward improving conditions. With that said, there is nothing simple about PAR in its conceptualization or implementation. It is marked by a blurring of the line between the researcher and the researched, as well as blatant challenges to notions of hierarchy in the pursuit of producing knowledge.

PAR presents a significant epistemological challenge to the established conventions of research. The research literature can be confusing and onerous to work through for new scholars, as leading proponents refer to PAR alternatively as a paradigm, a methodology and a method, which can be used in both qualitative and quantitative research. PAR aims to replace a detached and often imperial model of social research with a process that seeks to empower people who are typically seen as research subjects. The intention of PAR researchers is "to transform an alienating 'Fordist' mode of academic production into a more flexible and socially owned process" Kindon et al. (2007, p. 1). There is no rule book for PAR, and there is a resistance by many scholars to label it a methodology. Fine (2017) indicates a preference for the label epistemology, while seminal PAR scholar McTaggart (1994) describes PAR as "a series of commitments to observe and problematise through practice the principles for conducting social enquiry" (p. 315). As Chevalier and Buckles surmises, PAR is engaged inquiry, "that promotes pluralism and creativity in the art of discovering the world and making it better at the same time" (p. 3).

PAR's approach accommodates a wide range of theoretical orientations and methods. Like social work, the theoretical roots of PAR come from a range of disciplines, and it has also created theories and approaches which are uniquely its own. Participatory action emerged from the work of Kurt Lewin in social psychology, John Dewey in education, and Paulo Freire's *Pedagogy of the Oppressed*. Connected to grassroots organizing and liberatory movements, PAR's is rooted in work with the marginalised and disenfranchised. This form of research engages "a range of theoretical sources including feminism, poststructuralism, marxism and critical theory as they take shape through pragmatic psychology, critical thinking, practices of democracy, liberationist thought, humanist and transpersonal psychology, constructionist theory, systems thinking, critical race theory and complexity theory" (Kindon et al., 2007, p. 13). As the use of PAR has stretched across many disciplines, like Anansi the Spider, a trickster very familiar to Caribbean people, it has shown a propensity to morph into many forms, but always with a commitment to underscoring the importance of fairness, reciprocity, and seeking to hold those in positions of power accountable.

Blum et al. (2010) succinctly frames PAR as having three distinctive components: (a) it involves research – i.e., the systematic organized study of a subject; (b) it is participatory and collaborative in its method; and (c) it features action or some change by its process or outcome. Without all of these elements, a researcher attempting to complete PAR can easily find themselves instead pursuing action research or participatory/community-based research. Action research involves action but is not participatory in terms of involving all of a project's stakeholders. Community-based research or participatory research on the other hand, is collaborative in nature, there is a focus on an action outcome, but the community development and investigative processes are emphasised. While action research, participatory and community-based research and PAR are all post-positivist approaches, each has a distinct goal.

What makes PAR distinctive is the iterative process denoted by *reflect*, *plan*, *act* (O'Leary, 2017) established by action research theory and practice, but *with* the engagement of research participants in these cycles. As such, PAR studies are cyclical endeavours which requires reflexive practice and constant re-engagement with emerging data. In PAR, a plan is made to investigate an identified issue, an action is then carried out, followed by reflection on that action. A successive cycle of research is then initiated based on the reflection previously carried out. The cyclical process of reflect, plan, act is repeated until research participants feel satisfied that a meaningful change has been achieved.

Social Work Research as Practice: A Case for PAR

PAR's heritage is tied up with reclamation, resistance and liberation, specifically from oppressive forces and the residue it left on colonized systems and colonized minds. PAR's roots can be traced to the 1960's and 1970's, when politically progressive intellectuals, like Brazilian educator Paulo Freire and Colombian sociologist Orlando Fals Borda, were utilizing research as a tool for consciousness-raising and political organizing. In this period, there were many scholars engaging in research as a subversive practice, intentionally troubling colonial notions about which members of society were qualified and entitled to be knowledge producers, lead communities, and dictate social and economic policies.

In Caribbean scholarship, Walter Rodney's participatory approach to qualitative inquiry, *Groundings* (Rodney et al., 2019), was a quest to co-create knowledge with grassroots community members. Rodney was one of many Caribbean scholars who have worked towards "disrupting and transforming the institution of research…they are mindful of the communities they serve and respect participant researchers … they centre from the margins and legitimize forms of [indigenous] knowledge" (Stewart, 2019, p. 5). Stewart's (2019) *Decolonizing Qualitative Approaches: For and by the Caribbean*, focuses on ways in which researchers are decolonising frames and methodologies to produce knowledge about Caribbean people. Featuring work across academic disciplines, this text highlights the ways in which researchers have been using collaborative, empowerment focussed innovative work to privilege ways of knowing rooted in Caribbean sociocultural realities. Moreover, there is a call made for researchers to disrupt the colonial gaze within us, and unlearn our hegemonic education and training, by "truly getting to know their authentic self from an intersectional perspective" (Tuitt, 2019, p. 210). Tuitt (2019) contends that it is only through this path that researchers can "increase the likelihood of unleashing their emancipatory imagination to actualize Caribbean centered research and praxis" (p. 210). With reflexivity as a cornerstone of our discipline, this call should resonate strongly with social work researchers.

Contextual research that straddles social action, advocacy, and direct practice is essential to Caribbean social work. Thyer (2010) points out that as "a practice profession, not an academic discipline studying things for their own sake... [social workers] are expected … to develop effective solutions to problems" (p. 820). While both empirical research and applied research are integral to the development of social work, the discipline's need to focus on the latter is even more pronounced in the Caribbean context. For our researchers and practitioners, understanding psychosocial phenomena is bounded up with unravelling a tangled history of colonization, forced and voluntary migration and the full gamut of its' social problems. PAR offers a unique opportunity for Caribbean social work researchers to engage in knowledge generation steeped in the discipline's core values, yet informed by culturally situated approaches.

The social work researcher is essentially a practitioner engrossed in a "planned change process," intervening at micro and macro levels of social systems, to gather data and, in some instances, translate knowledge into action (Morris, 2006). Resonating with these pragmatic obligations, Hardwick et al. (2015), note that social work research should include,

> a primary focus on 'problematic/ problematised' areas of human activity; the expectation of being closely engaged with practice; a value-based concern to foreground the perspective and interests of service users; and arising from these, a consequent need to develop original and creative investigative strategies (p. 12)

In the two research projects, which I will address subsequently, PAR was able to meet all of the above-mentioned criteria in impactful ways. These PAR studies demonstrate a responsiveness to Barrow's (2009) call for social science research that uses in-depth, qualitative understandings of the cognitive, emotional, and behavioural world of Caribbean people. Focusing on two marginalised groups, young people living with HIV (YPLWH) and people living with mental illness, these PAR studies focus on problematised areas of human realities. In each group, the vulnerability faced are both intrinsic and extrinsic to the individual. While YPLWH are susceptible to risk because of a medical

condition, they are also made vulnerable by social conditions and systems that assign blame, shame, and stigma to their lived experience. Similarly, while people living with mental illnesses are managing health conditions that disrupt cognitions, emotions, and behaviours, they are also managing relational meaning-making and social structures that devalue their identity and create barriers to accessing a range of social commodities.

As a researcher oriented in an academic discipline which is also a value-based profession, I enter investigations with a commitment to anti-oppressive practice. In essence I am pre-wired for advocacy and committed to participating in some level of change to improve conditions and to work across the micro-macro divide. With social action as an ultimate goal, PAR is primed to function as social work practice.

Two PAR Studies conducted in Trinidad and Tobago

In this section I will briefly describe two PAR studies, one in which I was the sole researcher and another in which I was the principal investigator with two co-investigators, a photographer and a creative arts therapist/mental health professional. Each of these studies employed multiple cycles of *reflect*, *plan*, *act* and produced research outputs in the forms of exhibitions, documentaries, and performance/art installations which engaged public audiences. Before describing these studies, it is important to note that PAR often uses a range of methods. Kindon et al. (2007) note that PAR practitioners are often interdisciplinary scholars or work in interdisciplinary teams. Discussing the use of urban photography for social work research, Robinson (2007) notes that "incorporating multiple viewpoints and retaining a transferability to various intellectual projects" (p. 307) strengthens participatory research. Robinson continues by adding that "working across disciplines for a common aim must be approached as a continuous challenge, to ensure clarity of insight from multiple perspectives" (p. 307).

There is a lack of consensus around the meaning of "transdisciplinary" and "interdisciplinary" in the research literature and the terms are often used interchangeably (Nicolescu, 2014; Schmalz et al., 2019). With that said, definitions of interdisciplinary commonly describe the use of ideas, methods, or concepts from more than one discipline towards answering a single research question or exploring a research topic. While transdisciplinary research can also be interdisciplinary, it goes a step further and transcends the limits of disciplines by being action-oriented and seeks to understand "the present world, of which one of the imperatives is the unity of knowledge" (Nicolescu, 2014). Gehlert (2015) identifies three attributes of social work which uniquely positions practitioners to contribute to transdisciplinary research, namely a "deep understanding of social determinants of human problems," "the discipline's natural ability to draw together and integrate knowledge from a variety of other disciplines" and "its long-standing engagement with communities" (pp. 3–4).

The two PAR studies herein discussed were transdisciplinary research projects which included arts based methods, namely photovoice, portraiture, mixed media art, dance choreography, and found poetry. Photovoice is classified as a PAR method that firstly draws tacit, subjective insider-oriented data and secondly stimulates action and change among individuals and groups which are marginalised or characteristically voiceless in public spheres. Explicitly addressing dynamics of power in knowledge production, photovoice emerged during the 1990's (Wang, 1999; Wang et al., 1998) as a creative

approach that engaged participants in critical reflection as well as catalysts for personal and community change. A public exhibition/ dissemination of findings takes the form of a public exhibition of photographs taken by participants (Photo) with short descriptive vignettes written by the photographers (Voice). Jarldorn (2019) notes that "images can help us express emotions, providing different ways of seeing…as a visual language, photographs that have been purposefully created can generate a connection with the viewer—a visual conversation with the potential to convey complex concepts and ideas" (p. 15).

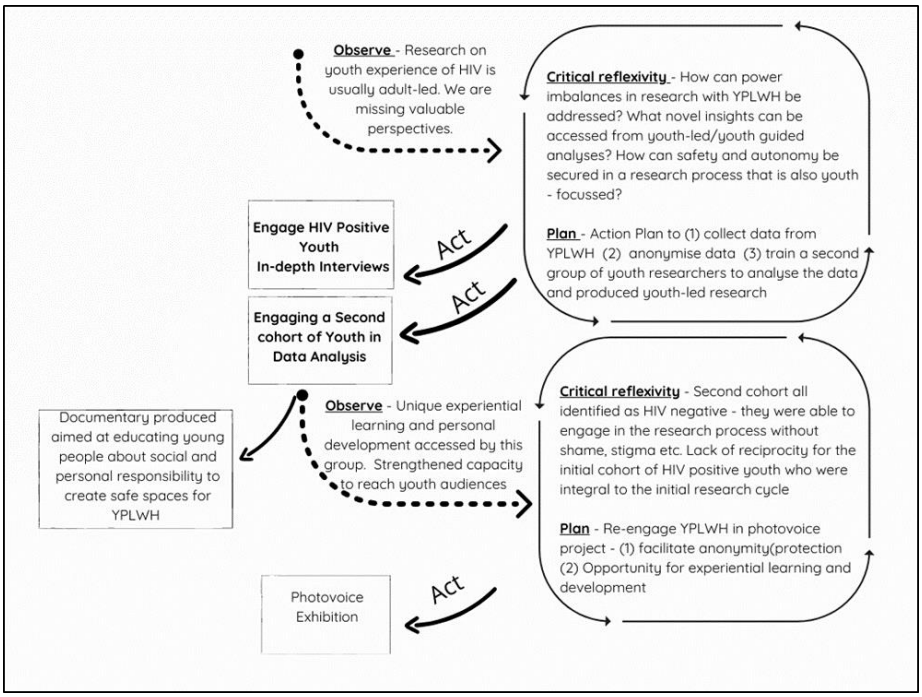
Arts Based Research (ABR) is a research methodology in its own right and is differentiated from qualitative research in the literature (Leavy, 2020). While qualitative research approaches may use art to present data, ABR uses art to generate data, analyze data, and or disseminate evidence. In one of the PAR studies described below, the participants and research team used portraiture, movement, and art making for data generation, analysis and dissemination.

In the Silence of my Skin: Negotiating HIV Disclosure

This study utilised youth PAR (YPAR) which is a specialised form of PAR, to investigate how young people perceived and managed disclosure of their HIV status. Addressing the distinguishing qualities of YPAR, Cammarota and Fine (2008) forward that this type of research with youth is "designed to contest and transform systems and institutions to produce greater justice" (p. 3). These researchers detail three types of justice; distributive justice, procedural justice, and a justice of recognition, or respect. YPAR hones in on the ways in which social structures disempower young people and relate to them in deficit oriented instead of asset oriented ways. "Righting" (Cammarota & Fine, 2008, p. 5) this injustice is an overt motive in the ways in which this type of youth-led research is conceptualised and implemented. Figure 1 illustrates the reflect, plan, act cycles of the *In the Silence of our Skin* study which is initiated by observations around the dominance of adult perspectives about youth experiences of living with HIV.

Figure 1

PAR Cycles- In the Silence of our Skin



The first cycle of engagement in this study involved in-depth interviews with six YPLWH. These in-depth interviews explored their meaning-making processes, cognitions, emotions, and specifically their psychosocial support needs around HIV disclosure. The second cycle of research involved training a second group of 10 young people between the ages of 18 and 25 to conduct constructivist grounded theory data analysis – this second group of young people are hereafter referred to as youth collaborators. The youth collaborators analysed anonymised transcript data of the in-depth interviews I conducted prior with the YPLWH. HIV status was not used as an inclusion criterion for the participation of the second cohort. Although this group of participants was not asked to disclose their HIV status, they all identified as HIV negative and their positionality was central to their data analysis. The youth collaborators created a documentary, to not only disseminate their findings, but focus on sharing their experience of learning with other young people. They used the opportunity to analyse and discuss how their perspectives around human rights of YPLWH changed drastically during the research process. They sought to engage in consciousness-raising among their peers to promote the understanding that creating safe spaces for HIV disclosure was a collective responsibility, instead of an obligation of HIV positive young people.

Overall, the youth collaborators reported that they felt empowered and capable of leading informed conversations on HIV and its psychosocial impact. They disclosed that the research experience taught them that on one hand, they "were well educated about HIV" but on the other hand, they "understood very little about it." Reflecting on changes in personal perspectives, one youth collaborator offered that:

> The stories were not distilled, sanitized or fictional, but real. Not the cartoon caricatures on a pamphlet but real lives. We became aware of the lack of social and infrastructural support for persons dealing with this disease. We understood that the biology aspects of HIV is one-quarter of the issue and actually the easiest bits to understand. It's the other stuff, the psychosocial stuff that we need to speak about.

Reflecting on the overwhelming benefits which the second group of young people were able to gain from the research experience, I was struck by the lack of reciprocity for the six YPLWH who started the research cycles. After engaging in critical reflection, I decided to reengage the six YPLWH through a photovoice project. Five of the six YPLWH who were initially interviewed, agreed to participate. Over the period of several weeks, these five participants learned basic photography skills, were given cameras and documented their lived experiences of managing HIV disclosure.

An exhibition, which the participants entitled *In the Silence of my Skin,* was mounted and opened to the public (see Figure 2). The exhibition, which included the documentary produced by the youth collaborators, ran for 2 weeks and was viewed by high school students as well as a cross-section of professionals involved in HIV treatment and service provision.

Figure 2

Photovoice Exhibition Flyer

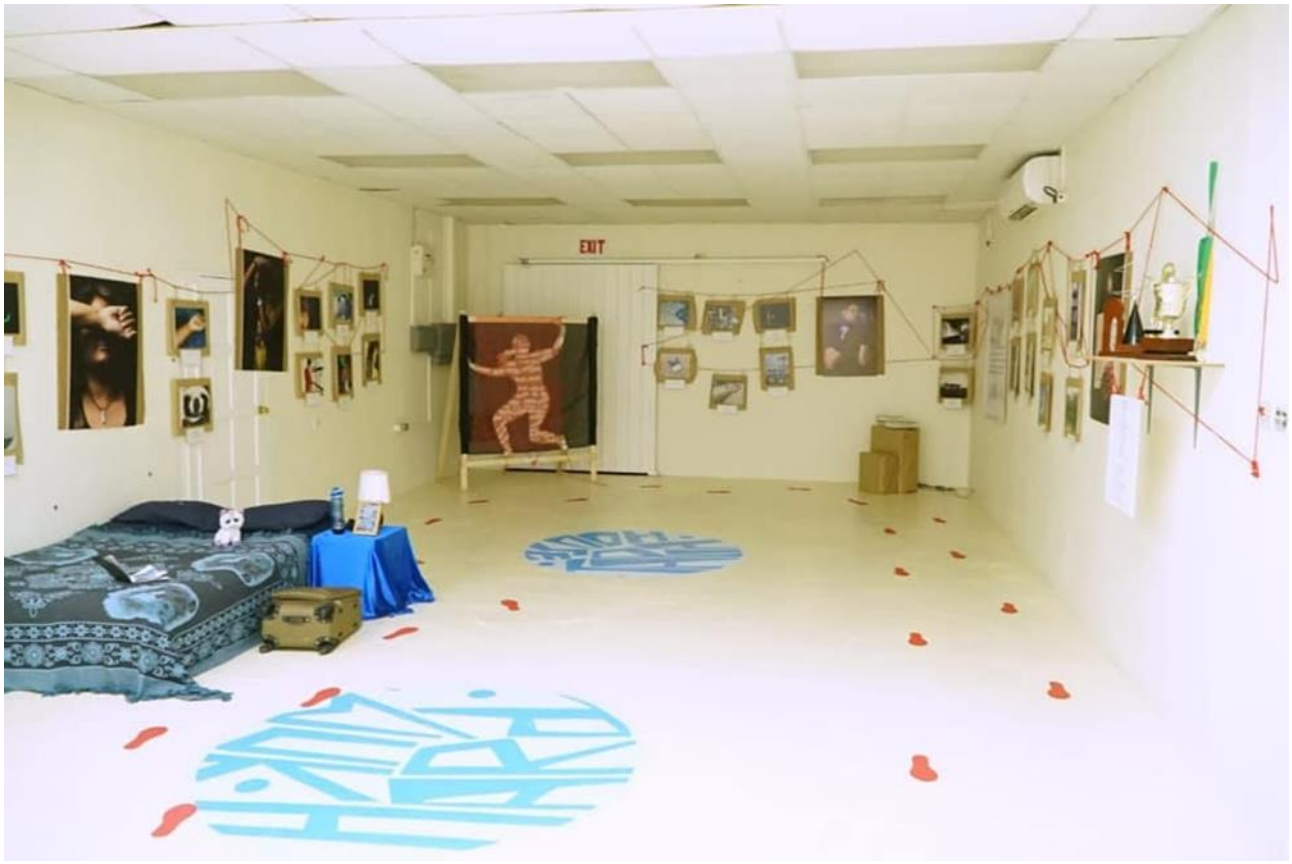
"Why you wanna fly?" Interrogating Felt and Enacted Stigma Related to Mental Illness through Multimethod ABR and PAR

Stigma is a devastating experience lodged deeply in the inner world of the stigmatized but enacted in multiple relationships across ecological systems. Five participants diagnosed with depression, anxiety, and schizophrenia were engaged for the study. The first cycle of research commenced with a photovoice project. Through 9 weeks of group discussions and reflections, participants unpacked the realities of living with a mental illness within the sociocultural context of Trinidad and Tobago. The participants took photographs, recalled periods of their lives when they struggled with mania, hallucinations, delusions, depression, suicide attempts, and intense feelings of pain, rejection, frustration, and anger. Through the inquiry they traced their journeys in coming to terms with living with mental illness. Finding a way to create from, and express intimate experiences was an emotional and liberating journey, at the end of which they found community with each other.

The week after one intense session of sharing, one participant returned and expressed how "heavy" and "exposed" he felt in his body. Through our discussions we became curious about exploring what stigma felt like in the body – both the feelings of heaviness which the participants interpreted as internalised or felt stigma, and feelings of exposure which was aligned with enacted or social stigma. This led to a second research cycle in which we begun to explore translating and materializing the experience of felt and enacted stigma in the body through art and art making. ABR methods in the form of portraiture, dance choreography, installation art, and found poetry emerged as a way to generate, analyse and represent data that could invite participants not only to view an exhibition, but to inhabit the world of the participants. What started as a photovoice exhibition became an immersive arts based and performance arts installation entitled, *Why you wanna fly?* Figure 3 depicts the exhibition, which contained portraitures, and five art installations for each of the participants, inviting the audience to inhabit their world. We also worked with two dancers to translate data into movement. The choreographed piece was performed at the opening night of the exhibition.

Figure 3

Exhibition Hall – Why you wanna Fly?



The exhibition functioned as a liminal site where audiences engaged in critical and transformative dialogues as they were invited to interrogate stigma related to mental illness. Audience members were also invited to create response art before leaving the exhibition. The response art prompts were *What were your thoughts? How do you feel?* and *What will you do now?* These prompts were used to connect experiencing the exhibition both cognitively and emotionally, with concrete actions that could follow to contribute to creating safety for people living with mental illness.

Pillars of Engagement in PAR

A distinguishable feature of PAR is its' commitment to rendering research accessible in deliberate and visceral ways. PAR facilitates distinctive opportunities for analyzing and interpreting evidence to which participants are uniquely qualified to speak. Arguing for the theoretical value of service-user and survivor-led research, Beresford (2005) makes the case that "knowledge is more reliable and valid when the interpretation of direct experience is closer to it, rather than further away as has traditionally been argued" (p. 9). It is out of this type of engagement that personal and social change can be imagined and endeavoured. PAR drives thinking and practice that is pragmatic, geared towards problem solving, has a psychosocial focus on awareness building and transformative learning,

and adopts a critical-emancipatory struggle for greater social justice (Chevalier & Buckles, 2019). It also provides a foundation for knowledge building which is informed by the direct experience of participants.

In both of the herein described PAR projects, the "knowing" and the "doing," the "research" and the "practice," as described by Shaw and Holland (2015) at the beginning of this article, is made possible in PAR. This is done by building emotional awareness, supportive relationships, community awareness, as well as facilitating personal interrogations around complicity with social problems and possibilities to participate in actions that promote change. Four mechanisms were critical to facilitating the generation of rich textured, multidimensional knowledge in these studies, namely, reflective practice, creating dialogic spaces, critical reflection, and dissemination

Figure 4

Pillars of Engagement: Translating Research to Practice

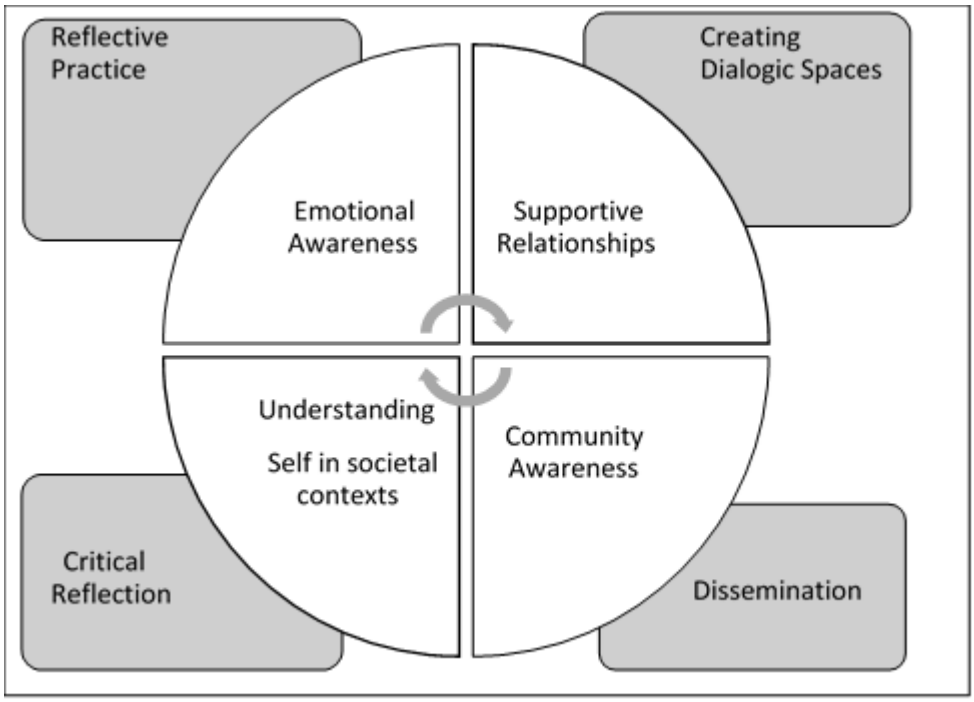


Figure 4 depicts two domains of engagement and practice; one domain has a focus on developing personal competence among participants, while the other has a focus on developing community and relational competence between participants and members of their wider community.

Reflective practice & Critical reflection

In the domain of developing personal competence, reflective practice and critical reflection were crucial elements of building emotional awareness as well as understanding self in societal contexts. Fook's (2015) differentiation between reflective practice and critical reflection are herein used. Reflective practice is defined as assessing your personal beliefs and examining assumptions which are supported by personal convictions and emotions, whereas critical reflection is reflective practice that "focuses on the power dimensions of assumptive thinking" (p. 443). I defined reflection for

participants as a way of looking at the interplay between thoughts and feelings and how these inform our actions. Participants actively engaged in questions like: *What was I assuming? What beliefs did I have? What are my most important values?* I defined critical reflection as examining the relationship between personal beliefs and social structures to determine what social and cultural influences, assumptions or knowledge may be affecting your actions. Critical reflection questions included: *How has my thinking changed? What might I do differently now? How do I see my own power? Can I use my power differently? Do I need to change my ideas about myself or situations?* (Fook, 2015). Reflective and critical reflective practices became essential for building emotional awareness, which informed key decisions in the research process, and thereafter propelled social action. For illustrative purposes, examples of a few responsive research turns that propelled action are discussed.

Recall that in the YPAR project, there were 2 groups of youth researchers; a group of six YPLWH (five of who were re-engaged for the photovoice study) and a group of 10 youth collaborators who were recruited to conduct data analysis. This research design was created to privilege youth perspectives in data analysis. The main tasks of the youth collaborators were coding, creating categories, constructs and themes and disseminating their findings. As part of their reflective practice, these participants were asked to critically assess how participating in data analysis discussions influenced their thoughts and feelings and, how these were in turn impacting their ability to complete research tasks. The participants' reflections through research journals, and group discussions, informed the creation of the documentary they eventually scripted. The original plan for the documentary was to disseminate their findings on HIV disclosure for young people; instead, the participants chose to disseminate their findings about ***how*** participating in data analysis impacted them. The final documentary became a call to action for young people to engage in activism. These youth participants questioned themselves in ways in which they had not previously anticipated, critically reflecting on their positionality – which included being HIV negative. Questions as, *How can I use my power differently? What ideas about myself or situations should be reconsidered?* led to moments of insight and internal interrogating of behaviours they had previously taken for granted.

The central task for the YPLWH was taking photographs and creating vignettes as they documented their experiences around HIV disclosure. During our weekly meetings, participants reflected on the experience of participating in group discussions about disclosure. The theme of invisibility and coping with the secrecy that shrouded their day-to-day interactions reoccurred. The participants were eventually able to discuss what it felt like to be seen by the group. By the end of the PAR sessions, these participants became a significant source of support for each other and their relationships have continued beyond the life of the project.

In the PAR project with participants living with mental illness, a significant reflective prompt was *what does stigma feel like in your body?* The invitation to locate self in the research picture, directed the participants to stop engaging in the research task at hand, and become aware of the emotions behind the action being performed. The new task for the research participants, and the members of the research team, was to let emotional awareness dictate the next steps. This in turn let to added dimensions of the study, including the use of ABR methods for data capture and analysis.

During PAR, participants make a collective commitment to understand a problem through engaging in both self, and collective reflection, and simultaneously carrying out individual or collective

action (Jarldorn, 2019). There is a reciprocal relationship between reflective practice and critical reflection. It was through this process that participants in both PAR projects were able to confront discrimination and examine prejudice as core processes.

Creating Dialogic Spaces & Dissemination

Owing to the cyclical nature of its inquiry, PAR has a call and response quality which creates opportunities for various exchanges - creating space for a dialogue amongst participants, between participants and researchers, connecting researchers to research audiences, between participants and policy-makers etc. Rowell et al. (2017) argues that "stretching dialogical spaces enables self-reflexivity and allows us to 'grapple with the complexities'" of PAR (p. 92). Furthermore, the authors make the point that dialogical spaces are sites for "constructing shared meanings, generating knowledge flows, and growing and nurturing community" (p. 99). The dialogic approach of PAR builds relational and community competence. The call and response happens during the research process and during research dissemination. The latter is an essential facet of PAR studies that can take diverse forms, ranging from exhibitions to Orlando Fals Borda's use of graphic histories, testimonial literature and chronicles made accessible to readers with minimal schooling (Rapapport, 2020).

In the Silence of my Skin took audiences through photographs organized around six themes: Medication and Education, Family and Inspiration, Identity, Struggles, Society, Truth and Faith. Each of the thematic areas created by participants disclosed different dimensions of HIV disclosure for young people. After journeying through the exhibition, audience members were asked to write messages to the participants. With markers, paint and chalk, diverse groups, from health care practitioners, to high school students on school outings with their teachers, to University based students and youth policy makers, used the opportunity to share their thoughts and feelings. Two weeks after opening night, there were scores of messages written to the participants on a large sheet of thick brown cotton. The messages had a common thread – they communicated to the participants that they were seen. This stood in sharp contrast to the sentiments of invisibility expressed from the initial in-depth interviews through to the exhibition. The many notes, some addressed directly to the pseudonyms the participants gave themselves, were direct responses to the silence and secrecy which the young people felt imprisoned them in their bodies. They presented opportunities for youth as well as other members of the public to witness and engage in discussions about the experience of being young and HIV positive.

Why you wanna fly consisted of 35 photographs, six art installations and found poetry. Each installation invited the audience to enter the lives of the participants in varied ways. For example, one installation was a replica of a participant's bedroom which contained several symbols including a self-authored book of poems. Another installation consisted of a life size cut-out of a female figure in a wooden box. The cut-out included transcript data from a life story interview, where a participant described feelings of entrapment and suicidal ideation connected to her experience of stigma. Audience members were also invited to co-create an art piece in response to the exhibition. Using art materials, which included paint, markers, wool, paper, and glue etc., each participant created art related to the prompts: *What were your thoughts? How do you feel?* and *What will you do now?*

Epistemology, Ethics and Engagement in PAR

I have argued that as a social work researcher approaching PAR grounded in core social work values, principles, and strategies, that I have ultimately engaged in research that is a form of social work practice. PAR presents unique ethical challenges as the most insidious of potential dilemmas are relational and involve issues of autonomy, power, and beneficence. Lake and Wendland (2018) notes that PAR is "particularly susceptible to what can be characterized as a potentially dangerous" practice (p. 35). Furthermore, they argue that both traditional/conventional research review processes, and "at times arrogant rejection of the ethical and legal oversight of external review" (p. 35) by PAR practitioners, contribute to this perception.

Blake (2007) in *Formality and Friendship: Research Ethics Review and Participatory Action Research*, notes that the ethical tensions in PAR often have roots in the ways in which the approach "diverges from the scientific tradition through the subjectivity of the researcher, and the relationships that form between the researcher and the researched" (p. 412). In both of the studies discussed in this article, relationships between the researcher and the participants, as well as among the participants, were integral to producing the results. The nature of these relationships operated beyond the scope of traditional research relationships. While participants in traditional qualitative research, may engage in one or two, 60 to 90 minute interviews, the young people in the PAR project engaged in interviews and discussion groups over a period of approximately 12 months. They spent many hours in active communication, and they formed a support group that continues to function several years after the end of the project. They have lost two group members, one, a young person who died from an AIDS -related illness and the other, a community worker and activist (an adult involved in the research project), who died as a result of cancer. We have also supported another member through gender transitioning. The group that worked on the mental illness and stigma PAR, a more recent research project, spent approximately 60 hours in individual interviews, group discussions, and mounting the exhibition over a 3-month period. Our research relationships are marked by friendliness, an affability which is inevitable as much as it is essential to the synergy that produces the work. As a social work researcher employing PAR, friendliness is a quality that I will not apologise for nor attempt to erase. My experience aligns with Cahill's et al. (2010) sentiments regarding PAR work with young people around immigration where they note that "emotion was not only a point of analysis but … was central to the inquiry" (p. 159).

A relational ethics approach is widely used by PAR practitioners as we aspire for transparent and self-reflexive ways to engage with the associated risks and challenges. Since PAR is characteristically a response to power differentials, "self-reflexivity, the practice of critically reflecting on how one's own identity, experiences, and positionality contribute to systems of power and oppression" (Lake & Wendland, 2018, p. 22) becomes indispensable. The core elements of relational ethics are mutual respect, relational engagement, embodiment, uncertainty and vulnerability, and creating an interdependent environment (Austin, 2015).

Transparency is therefore crucial to developing and sustaining respect, and in these PAR projects it was fundamental to the work undertaken. Like other forms of social work practice, as community work and case work for example, boundaries and limits are communicated, and reinforced and there are occasions when clients make requests or behave in ways that push these limits. In

these instances, roles and terms of engagement are reinforced. There were occasions in these projects when ethical dilemmas occurred; some were easy to address, and others were addressed with feelings of ambivalence. I suspect in a conventional research relationship these dilemmas may not have arisen, and furthermore, that the friendliness and informality of our relationships played into these dynamics. I will briefly address two such instances: a participant's request for a loan and my decision to exclude a specific photograph in one exhibition against a participant's expressed wishes because it conflicted with the ethical protocol approved by the Institutional Ethics Review Board (IRB).

The first dilemma was easily addressed, however I had to do so by openly acknowledging that after working together for such a long period, it was understandable why asking for help felt natural. I connected the participant to resources, but in doing so I did not simply pass on a referral list as would typically occur. Our relational engagement required greater involvement. Upholding the decision to exclude a photograph taken by a participant (who was over 18 years old at the time) based on an IRB decision, was the most difficult of the dilemmas. In retrospect, if I were not a novice researcher at the time pursuing doctoral work, I would likely have appealed the IRB decision. However, the incident was indicative of a truth about PAR for those of us who wish to romanticise the notion of equal power sharing in research partnerships - there are indeed limits to power sharing. When we designate young people as "co-researchers" it is unethical to not delineate that there are power differentials and other dominant dynamics that can dictate research decisions and limit their agency.

Although my role as a researcher was explicitly outlined at the start of the project, a relational approach to ethics advocates for navigating uncertainty in a way that honours the emancipatory intent and the complexity of the evolving nature of research relationships (Austin, 2015). PAR researchers should not pretend that these tensions and challenges do not exist, nor should they shy away from attending to them. Ethical participatory research demands a recognition of collective reflexivity as an essential practice for addressing ethical challenges that may arise. Austin (2015) points out that "the mutuality of participatory research extends to vulnerability" (2015, p. 33). Self-reflexivity and meaningful oversight are therefore essential to developing an ethically sound yet vulnerable research practice. In the project with young people, supervision was crucial to working through dilemmas; while in the study on stigma and mental illness, peer supervision was indispensable. Securing IRB approval for both studies involved dialogue about participatory ethics which fell outside of the conventional submissions the committees usually received. These were by no means smooth processes.

On a final note on the ethical implications of the epistemology of this approach when seen as social work practice, the fluid and evolving nature of iterative PAR cycles is noteworthy. In a similar manner to social work practice, after termination occurs, reengagement may be initiated by either the client or the practitioner, at which time it is the responsibility of the practitioner to outline the new terms of engagement. In the YPAR project, we all agreed to terminate the research after the exhibition and release of the documentary, however, opportunities to do continual educational work subsequently arose. The participants continued to work on an HIV disclosure policy for a residential care institution and also partnered with two government agencies on HIV awareness-raising projects. This is yet another example of how PAR does not fit into neat social science research boxes as it tends not to have clear boundaries with definitive start and end points.

Conclusion

PAR aspires toward social change yet often, as is the case with the studies described in this article, work with small groups of participants. The power of PAR however, is its ability to move beyond individual conditions while working within them. PAR is strengths based because it evolves from a conceptual frame that views marginalised groups from an assets-oriented instead of deficit oriented approach. In so doing, PAR works with people who characteristically cannot access circles of influence and decision making regarding an issue in which they have a vested interest. Through research participation, they can rescript inaccurate descriptions of marginalised groups and engage in decision making processes in previously unimagined ways. The work engaged in and produced can only be facilitated by tapping into participants' strengths. For vulnerable groups who are often framed in deficit oriented ways in social arrangements across micro and macro levels, participating in PAR is an opportunity to reframe the narrative for themselves as well as for others.

The participants in these studies conceptualised and mounted exhibitions and produced a documentary. These research outputs engaged a wide spectrum of audiences including but not limited to, in and out of school youth, service providers across various fields as well as policy makers. These actions with entities outside of the academy, supersede the typical engagement of researchers using conventional research approaches. What constitutes "action" in this type of research is the engagement of participants in ***doing***; an engagement that moves them beyond participating in research interviews or discussions. They are actively involved in creating something that did not exist before, out of evidence they generated during the research process. Once participants engage others with their novel research product(s), that action can now stimulate further action in other social domains. These research products are not dissemination exercises but a form of praxis.

Powers and Allaman (2012) note that in youth PAR, young people use " their findings to consider alternatives and identify points of 'opening' where they can help change the status quo" (p. 1). These authors highlight that PAR initiates social change through a range of actions, from educational outreach to political lobbying. Following the exhibition, youth participants in the *In the Silence of my Skin* project convened a roundtable at the regional Caribbean HIV Conference: Strengthening Evidence to Achieve Sustainable Action. They were also engaged by two local government agencies (the Ministries of National Security and Social Development), through which they completed outreach work in a state institution, and participated in a national campaign and a public educational fair held at the Promenade in the city capital. These three projects were initiated by service providers and a technocrat who attended the initial exhibition and participated in the community dialogues facilitated by the participants. Udvarhelyi (2020) points out that action is "anything that disrupts existing relations of power and exclusion" (p. 26). For these participants, what begun as research into the experience of YPLWH around HIV disclosure (a micro/individual level phenomenon) has resulted in actions reaching into macro-level spheres. For example, one of the projects the young people engaged after the initial photovoice exhibition was drafting a youth HIV disclosure policy for a residential institution. This illustrates the capacity of PAR to bridge the micro-macro divide.

The PAR projects discussed produced results which were practice-oriented, utilized a problem-solving lens to facilitate an emancipatory experience for the participants and simultaneously sought to initiate social action and social change. Social work research and practice endeavour toward common

ends; they both mirror people's lives in context and share a mandate to improve everyday experiences of marginalised people. For the majority of our service users, their vulnerabilities are connected to social arrangements that disenfranchise and push them to the margins of society. As a result, the social work practitioner's call to serve, whether it be in the form of direct or indirect practice, is tied to connecting the improvement of the individual's lived experiences to the improvement of social conditions. PAR, as an empowerment, strengths-based, collaborative research practice, addresses vulnerabilities by concurrently investigating lived experiences, and making connections with oppressive social conditions in a tangible manner.

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