

(HOW) SHOULD I BE DOING THIS? PARTNERING IN RESEARCH WITH
A CONSUMER SURVIVOR INITIATIVE AS AN OUTSIDER MASTER'S
STUDENT

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A CONSUMER SURVIVOR INITIATIVE AS AN OUTSIDER MASTER'S
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A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the
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TITLE: (How) should I be doing this? Partnering in research with a consumer survivor initiative as an outsider master's student

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Abstract

Participatory action research (PAR) methodologies attract researchers both because they open up space to apply the values and principles associated with social justice and because they have the potential to deepen our understanding of an issue by giving us the opportunity to explore contexts and processes through people's experiences. This allows for new insights to emerge and relevant solutions to be discovered and implemented through emancipatory practices. However, choosing to do this type of research for a thesis as a master's of social work student without lived or research experience complicates an already complex endeavor and raises many dilemmas, questions and challenges. Reflecting on my experience of working with a peer-led community organization in Southern Ontario that provides services for people who have experienced mental health or substance use challenges and have interacted with the mental health system, this thesis will explore my journey of joining a research team that set out to use PAR to better understand peer support. Using a narrative inquiry approach, I will explore the tensions that occurred throughout the process of attempting PAR with a community agency within the university framework of completing a thesis. In the spirit of PAR and its intention to disrupt dominant approaches to research processes, I will use an alternative, storytelling format in order to best illustrate my circumstances, perspectives and the difficulties I faced as an outsider, student, university researcher trying to follow PAR principles. The lessons I learned will also be provided in an effort to make this type of

undertaking easier for future students. Overall, I learned that we need to find ways to bridge and support the two cultures of graduate students and community groups in working together in PAR.

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Introduction

I started my Master of Social Work (MSW) program with some trepidation because I was aware that there was a thesis component and I had no idea how I was going to get it done. My ambition was to engage in research that aligned with my values and had some real world impact, but beyond these two aspirations I was at a complete loss as to how and what I should research. I knew I was passionate about things like mental health, self-determination and creating environments where people can control their own lives, holistic approaches to health and wellness, social justice and facilitating social change, and generally disrupting the status quo in the name of equity and equality. However, as a student without lived or practical research experience and no work experience in any of these areas, I was feeling stuck and unable to focus on a specific research topic. This was why I jumped at the opportunity to be part of a research team within a mental health Consumer Survivor Initiative (hereafter referred to as the Initiative) that was beginning a participatory action research (PAR) project when the chance became available.

Unaware of what I was getting myself into, I learned that the process of doing this type of research within current university structures needs to be examined and revised because these two systems of knowledge production are different and can be incompatible with each other. The difficulties I encountered were not because of the actual PAR methods per se. The challenges arose because the culture of the two groups (peer support community and university/academic)

are different and there exists a mismatch between the fundamental ways of knowing and doing in PAR and the ways of knowing and doing in academia. PAR is a time, energy and resource consuming, collectivist, participatory process which contrasts graduate program requirements for individualistic knowledge creation with limitations in student time and resources. These differences are what created problems for me and are the reason I am not reporting on the results of the project I participated in, but on the process of being a student. The challenges I faced and the lessons I learned as an inexperienced student and outsider have become the focus of my thesis which, I hope, will contribute some original knowledge and insight, and make it easier for future master's students who are considering doing PAR with a community agency in order to fulfill their degree requirements.

I started my thesis process without knowing too much about PAR or completing a thesis and nothing at all about peer support or the intricacies of health research and knowledge making within all of these parameters. This necessitated searching for information on all of these topics and then trying to connect all of these ideas in order to start making sense of my experience. I will share with you, the reader, what I learned from the literature as I go so that you too can learn and begin to understand. To that end, I have arranged what I discovered as I discovered it in order for you to experience it in the same way that I did.

One of the first things that I had to think about and explore for this project was PAR itself. I knew a little about it from previous social work classes. What I remembered was that the main reasons participatory research methodologies attract researchers is because they open up space to apply values and principles associated with social justice and because they have the potential to deepen our understanding of an issue by giving us the opportunity to explore contexts and processes through people's experiences. This allows for new insights to emerge and relevant solutions to be discovered, developed, and implemented through emancipatory practices.¹⁻⁴ PAR is a values-based approach to research and is built on principles like understanding and challenging power imbalances; empowerment and self-determination; partnership and service user involvement; promoting human rights, well-being and quality of life; and advocacy. It is a strategy for changing systems while at the same time generating critical knowledge about systems.⁵ This kind of research is shaped and guided by the people affected by an issue, focuses on communities or local contexts, generates knowledge that is useful to those most directly affected by the issue, and facilitates social change leading to empowerment, equality, and social justice.^{5,6} What it attempts to provide is an alternative way to learn about the world, to share this knowledge with stakeholders and the public, and to use this knowledge to

¹ Baum, MacDougall & Smith, 2006

² Bennett, 2004

³ Hounsell & Owens, 2005

⁴ Russo, 2012

⁵ Shannon, 2013

⁶ Pain, Milledge & Whitman, 2011

change the way things are being done to ensure that processes, practices, policies and outcomes are more effective, equitable and just.^{7,8}

Along with the positives, however, I also came to understand that this kind of research is filled with ethical, political and methodological tensions, none of which were clear to me when I first heard about and decided to join a PAR project that was starting in my neighbourhood. What I now know from this experience is what follows, and in the spirit of action research and its quest to change how things are done, I present this information in an alternative format by making it look and sound more like a story. I did this for two reasons. One was that I found it impossible to explain this research project using a traditional format because it assumes a linear research process and therefore cannot accommodate the iterative cycles of planning, acting, observing, and reflecting of PAR. Second, using a story-like format is intended to more effectively represent my experience, reveal the realities of the context and activities of this project and the impact that these had on my life, and to take you on this journey with me. A thesis is typically written in a particular format which consists of sections presented as an introduction, a theoretical perspective, a critical analysis of the literature; a statement of the research problem, methodology, results, a discussion including implications for social work, and a conclusion. This kind of reporting procedure often loses significant information or presents it in a form that fails to adequately

⁷ Greene & Chambers, 2011

⁸ Ozanne & Saatcioglu, 2008

represent the complexity and significance of events that make up the reality of people's lives. I will incorporate the same elements, but in the order and way that they happened to me, along with the emotions, failures and achievements that occurred together with each step.⁹

Using a story format is compatible with and complementary to the method that I chose for my thesis. The method used is a narrative inquiry and it takes a critical and interpretive approach. Narrative inquiry is based on stories from an individual's life that can be told to share information or teach an important lesson.¹⁰ I chose this approach for some of the same reasons I chose to use a story format. One reason was as a way to counter the inherent weaknesses of conventional positivist research methods which are typically not capable of providing a holistic view of the complexities of the human experience.¹¹ A second reason was to counter dominant research beliefs that personal experience is not as valid a source of data as those gathered through quantitative methods.¹ And third, narrative inquiry allows for a focus on an individual (in this case, me) and my construction of knowledge.¹¹ I would like to use this thesis to push forward the idea that what I learned from this experience can be a basis of knowing and can lead to knowledge that can transform practice.¹ The critical and interpretive approach also creates space to challenge positivism and its

¹ Baum et al., 2006

⁹ Stringer, 2014

¹⁰ Martin, 2018

¹¹ Webster & Mertova, 2007

assumptions as well as interrogating the role that privilege and power play in knowledge production.¹²

The beginning: How it all got started

My research journey began when the professor of the first class in my MSW program provided us with a list of research opportunities that were going on out in the local community. These were projects that were open to our participation as a means by which to complete our MSW research. She mentioned a mental health organization in Southern Ontario that was looking for students to help them with a research project. This seemed like the answer to my thesis worries: joining an existing project involving mental health that had the potential to facilitate change while teaching me how to do it? Sounded perfect. After class, I asked for the contact information and then proceed to try to set up a meeting. It took some time to connect with the agency. After a few failed attempts and cancelled meetings, I tried not to take it personally and instead assumed that my contact must be a really busy person. I attributed this to the far-reaching impacts of our current neoliberal environment and the government's agenda of reductions in responsibility, services and spending which have resulted in increasing the demands placed on social service agencies.^{13,14} One of the many things that my social work education has taught me is that the transferring of public responsibility onto the market, nonprofit organizations and individuals has left

¹² Brydon-Miller, 2002

¹³ Harper & Speed, 2012

¹⁴ Howell & Voronka, 2012

employees with too many duties and responsibilities,¹⁵ and little time for activities like working with students and research projects.

We did, finally, set a day and time to meet. I was excited and arrived early. Unfortunately, my contact was not able to make it into the office due to illness, but we managed to connect by phone. We chatted about the organization and it was here that I learned a little more about who these people were and what they did. This agency provides peer-run education and support programs using a person-centered, recovery-based approach to people who have experienced mental health and/or substance use challenges and have interacted with the mental health system. The Initiative also strives to be leaders in finding ways to link the formal organizational and governmental needs of the health care system and health service providers with the culture and intent of peer support services. In order to advance both of these objectives, they were planning a research project that was going to explore peer support. At the end of our chat, my contact asked me what I thought about things so far. "Sounds great!" I said. And it did. Except that I did not really know what peer support work was or, at the time, what it would mean to try to do research for academic purposes in a peer-led environment. The next question she asked me was about my experience with mental health and/or substance use. I did not have any. The response I received was that this organization typically preferred for all of its members, including volunteers and students, to have experience with these issues, but that in this case

¹⁵ CUPE, 2014

"it should be fine". This was the point where I started to worry. Although we both agreed to move forward with my joining their research team, I felt that I needed to figure out if this was indeed going to be "fine". I decided to head straight home with a plan to start googling peer support.

On the drive back, I began thinking more about what it would mean for me to join this research project. I had left our first encounter feeling somewhat unsettled about my decision to help with the Initiative's work. This was because I was concerned about the type of research that I might be expected to do for my thesis and the fact that I did not have any experience with mental illness or substance use. Both of these things had the potential for me to bring some harm to the people at the Initiative and their research participants. In that moment I remembered the classes that I had taken in my undergraduate studies, particularly those that were about social work and Indigenous communities. We talked a lot in those classes about outsiders working with historically disadvantaged people, and how they frequently used (and continue to use) traditional research paradigms which are often insufficient, oppressive and exploitative.² The issue of the researcher as an outsider or an insider to the group being studied is an important one because the positionality of the researcher in relation to the participants influences all aspects of the research process including research design; formulating questions; and data collection, interpretation and use.¹⁶ Research like this is often viewed by communities as esoteric, irrelevant to community needs,

² Bennett, 2004

¹⁶ Corbin-Dwyer & Buckle, 2009

and incapable of contributing to solutions for the problems faced within the community. In addition, the processes and products of traditional research are treated as a commodity for academics who can exchange it with universities and publishers for benefits for themselves like advanced degrees, professional reputation, career mobility and book revenues. However, marginalized groups rarely capitalize on the commodification of their own cultural background and knowledge and when information appropriated by researchers from community sources becomes a commodity for private ends, it inherently becomes a process of alienation, and ultimately, oppressive.²

In these and other social work classes, we also discussed acceptable roles for an outsider when considering the possibility of working with marginalized groups and communities that have been historically subjected to such traditional (and largely) unexamined research and practices. I had learned that outsider roles generally should not go beyond providing help that is requested by the group or community; should be confined to a specific area that you are explicitly qualified in; and, more often than not, be confined to being an ally and advocate.^{17,18} The take away message for me at that time was clear: it is probably not my place to work within contexts and communities to which I do not belong.¹⁹ I related these ideas to my involvement in research with people who have experienced mental illnesses and the situation that I now found myself in. Not only would I (as

² Bennett, 2004

¹⁷ Baskin, 2011

¹⁸ Unsettling America, n.d

¹⁹ Aveling, 2013

someone without experience of mental health or substance use issues) be an outsider here, but, as a student, I did not (at the time) see myself as being an expert of any kind or having any qualifications or advantages that this organization could possibly need. Fortunately, as a part-time student I had begun working on my thesis early and had some extra time in order to learn, reflect and wait to see where the decision to participate in this project might take me.

Shortly after our first conversation, I began attending the Initiative's weekly research team meetings and this helped me to begin to understand more about the project in terms of how things were being done and my possible role in it. To give you a bit more background; the core research team was made up of four members. Three members were from the Initiative itself, all of whom had lived experience and were working in peer support. The fourth member also had related lived experience but was an outside consultant, brought into the Initiative as needed for special projects that required her particular skill set. These people had been working together for some time, and listening to them as they talked, I could feel their passion for peer support and the research they were planning to do. This made me want to do whatever I could to support their work, but it also gave me a sense of how they would organize the research process and everyone's place in it. After a few meetings, I felt like I understood what working within these circumstances would be like, and this soothed some of my anxieties (a bit).

Having learned from my previous classes that it is often the outsiders that hold the power, control and benefits in traditional style research with

marginalized groups, I wanted to make sure that I took every step possible to diminish these issues. Fortunately, the way the project was unfolding, I could see that I would be functioning as only one (junior) member of the team, therefore any role I was going to play would be a small, supportive, subordinate one, and this would limit the possibility of my being exploitative or oppressive. Further, many members of the team held bachelor's and master's degrees, and all had some combination of experience and knowledge as consumers/survivors, researchers and peer support workers, which, if anything, tipped the power relationships greatly in favour of the research team. This, along with my desire to support the team with their project (rather than doing my own, separate one within their organization), assured that the research remained under full control of the Initiative with the purpose of meeting a need they had identified as being important. Additionally, my involvement came at the request of the team who had asked for student help and had accepted me into their project knowing that I did not have lived experience. I assumed that this meant they were aware of any possible risks of having me on board, and felt that any benefits I could bring outweighed these. Moreover, being open about and recognizing that any work I did here would also be for my own academic gain, I was dedicated to making sure that whatever I did here would be with and for this organization and its goals. I was committed to being as helpful as I could to this group, and wanted to do everything "right". To help with this, I asked the team for any resources that they might recommend in order to learn as much as I could about peer support and

make sure I was on the right track with what I had learned on my own so far.

They steered me in the direction of a few pieces of literature that they felt were important. From there, I began finding additional sources to learn from.

Throughout the next sections, I will again share with you what I found out from all of the reading that I did. This is necessary to help lay the foundation of understanding so that you can connect it together with my journey as I had to do.

From the academic journals and literature from various organizations that I consulted, I came to understand that peer support is an approach to mental health services that attempts to redefine mental illness and intervention. It is based on the idea that people who have faced and overcome a difficult experience can offer support, encouragement, hope and mentorship to others facing a similar situation.^{20, 21} Although definitions vary somewhat, peer support can be broadly defined as any organized support provided by and for people with mental health illnesses and typically involves emotional and practical assistance. It is a way of providing services that are distinctly different from current discourses and practices that are highly medicalized and understand mental health and illness as a problem. Medical approaches tend to effect and reinforce stigmatization, limit practice to intervention by medical "experts" and ignore the many aspects of life that support wellness.²⁰ However, it is important to point out here that peer support is not meant to replace traditional clinical care but to complement it, and

²⁰ Cyr, McKee, O'Hagan & Priest, 2016

²¹ Davidson, Chinman, Sells, & Rowe, 2006

vice versa. Peer support values the bio-physical perspective that in many cases does assist people with mental illness, but it strives to address the political and social needs of the people they are servicing. It recognizes that wellness is a full life experience and considers the health of the whole person. The reduction or elimination of symptoms may be an important goal and so traditional mental health interventions may be necessary, but this is only one aspect of the person's experience.²²

I learned from doing this literature review that the roots of peer support lie in the disability rights movement and the emergence of social models of disability which have had some influence on treatment approaches and created a wider acceptance of mental illness.²³ The disability rights movement and social models of disability challenge the medical model and work to replace oppression and marginalization with empowerment and full inclusion by identifying and eliminating systemic barriers, negative attitudes and exclusion by society and by providing services that increase rights, choice, independence and self-determination.^{23,24} As well, I learned that the contemporary definition and processes of peer support were also influenced by civil/human rights movements whose agenda aligned with that of the disability rights movement and laid the foundation for former psychiatric patients to join together and form the consumer/survivor/ex-patient (c/s/x) movement.²⁵ This group of people came

²² Sunderland & Mishkin, 2013

²³ Bogg, 2010

²⁴ Winter, 2003

²⁵ Adame & Leitner, 2008

together because of the negative experiences they had with the traditional mental health system and had two goals in mind: to fight against the entrenched power of psychiatry; and to change the laws and develop public policies for those with a diagnosis of a mental illness.^{4,20,25}

In reviewing the literature, I found it interesting that collective psychiatric survivor advocacy has a long history in North America and Western Europe dating back to the Alleged Lunatics' Friend Society, which was established in England in 1845.²⁶ In North America the c/s/x movement gained momentum during the 1960's²⁶ and since the early 1970's diverse groups of former recipients of mental health services have mobilized for change in the mental health system.²⁷ The ex-patients who mobilized in the early 1970's were loosely organized into the Psychiatric Inmates Liberation Movement, one of many emancipatory civil and human rights liberation movements of the 1960's.²⁷ Over the last few decades many more ex-patients' rights groups have formed and developed professional contacts and alliances which have resulted in the creation of a larger, broad-based movement.²⁷ Today, this "international coalition of grassroots organizations" continues to work for human rights in the mental health system²⁸ by challenging the (still) dominant medical model with its harmful discourses of illness and deficits, advocating for the active involvement of service users in the design and

⁴ Russo, 2012

²⁰ Cyr et al., 2016

²⁵ Adame & Leitner, 2008

²⁶ Usar, 2014

²⁷ McLean, 2000

²⁸ Adame, 2014, p. 456

delivery of services in ways that move beyond "biology" to consider the effects of social conditions and contexts on mental health, and by promoting wellness and strengths through its values and principles.^{13,14,20,29,30}

I also learned that peer support, unlike traditional methods of treatment, finds it extremely important to be explicit about the values on which it is based. For this reason, peer-run organizations have been described as value-based services which is a term used to mean that these are mental health services that are seen as important by consumers but lack sufficient quantitative research on their effectiveness to call them evidence-based.^{20,31} This, as you too will see, I discovered connects with many of the challenges that the Initiative encountered throughout this project. The values of peer support center around three themes; self-determination and equality, mutuality and empathy, and recovery and hope²⁰ (recovery refers to living a satisfying, hopeful, and contributing life, even when a person may be experiencing ongoing symptoms of a mental health problem or illness³²). For peer support, these values are what guide both the processes and goals towards which policy and practice should be directed. This type of support is meant to create a trusting, safer and more accepting environment where people can talk openly, feel validated, share stories, exchange information and learn from

¹³ Harper & Speed, 2012

¹⁴ Howell & Voronka, 2012

²⁰ Cyr et al., 2016

²⁹ Loumpa, 2012

³⁰ Morrow & Weisser, 2012

³¹ Miyamoto & Sono, 2012

³² Mental Health Commission of Canada [MHCC], 2018

each other. This establishes a sense of community and belonging, one that is based on shared experiences and an understanding from those who have been through similar experiences. It is believed that this atmosphere allows people to develop self-esteem, hope, meaning and purpose, self-responsibility, and to experience empowerment and personal growth for both those who provide peer support and those who receive it. There is evidence that these types of changes can lead to more concrete outcomes for people, such as: better coping skills; better understanding of mental health issues and services; increased community engagement and less isolation; reaching life goals and experiencing a sense of accomplishment; and increased quality of life, all of which work to reduce crises and hospitalization.^{20,31}

So, through its recovery based, holistic and social justice orientations, peer support in mental health and addiction settings is intended to provide a wide range of benefits not only for those receiving the support, but also for peer-support workers themselves, and for the mental health system as a whole. For those receiving services, peer support offers an alternative world view (in terms of understanding mental health, illness, treatment/recovery, etc.), and a different set of values. These values allow for the provision of unique social, emotional and practical supports as well as facilitating justice-oriented objectives like addressing issues with power (both within the helping relationship and within society at

²⁰ Cyr et al., 2016

³¹ Miyamoto & Sono, 2012

large), understanding larger cultural and political issues, turning oppression into consciousness, and promoting change and action. This results in hope for a better future, experience of equal relationships (between the helper and the one being helped) and opportunities for learning about concepts of recovery, empowerment and self-determination. Combined with learning about the experiences of the peers who have been successful in their own recovery efforts, this peer support process can help people stay in recovery and may increase empowerment and the development of personal resourcefulness. This is what is thought to have the ability to improve people's lives and reduce the use of more formal mental health, medical, and social services and contribute to micro, mezzo and macro social and policy changes.^{20,25,29,31,33-37} Unfortunately, I learned that even though the milestones gained by advocates for this approach have led to the growth of this movement and a greater medical and societal acceptance of its beliefs and principles, changes to the system have been slow. Despite research evidence of the benefits,^{20,31,35,37} peer support programs have yet to receive the focus, funding, and attention they need in order to become a standard option in the health care system.³⁸

²⁰ Cyr et al., 2016

²⁵ Adame & Leitner, 2008

²⁹ Loumpa, 2012

³¹ Miyamoto & Sono, 2012

³³ Davidson, Bellamy, Guy & Miller, 2012

³⁴ Mead, Hilton & Curtis, 2001

³⁵ Ochocka, Nelson, Janzen, & Trainor, 2006

³⁶ Solomon, 2004

³⁷ Walker & Bryant, 2013

³⁸ MHCC, 2017

This literature search helped me to understand that this is where the Initiative's research came in. Their intention was to try to find ways to advance research and knowledge about peer support and its efficacy in order to support their advocacy activities and influence policies at the local level and beyond. And they wanted to do this using PAR because service user participation in research is consistent with peer support's principles and objectives and also provides a mechanism for people to examine the negative impact that mental illness has had on their identity, reconnect with the social world and regain some control over their lives.³⁹ The ultimate goal for the team was to facilitate peer support becoming offered as part of the standard range of services and supports in Canada's health care system. As the weeks went by, the discussions taking place in the team meetings to determine the direction of the research centered around these ideas and how to contribute to the knowledge base in ways that might move mental health practitioners and policy makers (many of whom remain unsure of the value and necessity of incorporating this approach as a standard option in addiction and mental health services) to change their minds. I wondered why peer support continues to be a questionable addition to services since there seems to be ample evidence of its benefits. I asked the team about this and they explained that the medical model continues to dictate which treatment options and services are made available to people with mental illness and substance use problems. They also suggested that this might be something that I could look into on my own. I

³⁹ Hutchinson & Lovell, 2013

wanted to know more and decided to explore the issue further by again returning to the literature.

My search of the literature confirmed that first, the medical profession and its ways of knowing and doing continue to maintain dominance in the field of mental health and second, that it also persists in challenging peer support's efficacy and its knowledge making processes, claiming that research in this area has been lacking or of low quality.⁴⁰⁻⁴² And while many studies find for the positive impacts of peer support, those that evaluate peer support from a positivist point of view comment on methodological shortcomings (because these studies tend to be qualitative), suggest that appropriate (quantitative) research is limited in number, and recommend that further research should be conducted with greater specificity, consistency, and rigor in order to strengthen the evidence. This group of literature reflects theoretical and methodological positioning that align with frameworks and beliefs common to most health research and appears to show a lack of understanding of peer support and its broader intentions of social justice and a holistic approach to health. This is evident by the fact that they too have investigated peer support using traditional scientific methods and have concluded that peer support provides no difference in outcomes (in terms of symptom reduction and hospital stays) when comparing the effectiveness of professional psychotherapists and treatment as usual (i.e., medication and psychotherapy) to

⁴⁰ Lloyd-Evans et al., 2014

⁴¹ Pfeiffer, Heisler, Piette, Rogers & Valenstein, 2011

⁴² Pitt et al., 2013

paraprofessionals like peer workers and therefore do not recommend making peer support a mandatory requirement in mental health services. Interestingly, these studies do admit that peer support provides outcomes for people receiving these services that traditional methods are unable to accomplish like positive effects on measures of hope, recovery and empowerment,^{33,36,40a-45} as well as being able to act as "a mechanism for challenging attitudes of clinical staff and contributing to culture change within mental health services".^{40b}

In spite of the many positive effects of peer support that have been recorded in multiple qualitative and quantitative studies, the literature was revealing that debates over what counts as evidence, whose knowledge matters and which processes and methods should be used to make these determinations were some of the major reasons that peer support was having a difficult time proving that it should be used as a complement to traditional clinical care. These problems, I found out, stem from the different belief systems or world views that guide various practitioners and researchers working in the mental health field, and the power and authority that each of these systems and views have (or do not have) to influence the way we understand and treat mental illness.⁴⁶ Fundamental

³³ Davidson et al., 2012

³⁶ Solomon, 2004

⁴⁰ Lloyd-Evans et al., 2014 (a)

⁴⁰ Lloyd-Evans et al., 2014, p. 48 (b)

⁴¹ Pfeiffer et al., 2011

⁴² Pitt et al., 2013

⁴³ Chinman et al., 2014

⁴⁴ Gillard, Gibson, Holley & Lucock, 2015

⁴⁵ Pistrang, Barker & Humphreys, 2008

⁴⁶ Denzin & Lincoln, 2018

elements such as the ontological, epistemological and methodological assumptions that form the distinctions between research paradigms create different ways of knowing and doing; each of which comes with a different level of legitimacy.^{1,46} Traditional scientific methods (which are grounded in a positivist framework) form the "gold standard" against which other types of research are judged. Interpretive paradigms (such as those that often inform peer support) continue to struggle to prove that they count just as much.^{1-4, 31,46} Being exposed to all of this information and perspectives on research methodologies and how they either influence or challenge varying perspectives led me down two more paths: one on how knowledge is created and supported in the field of mental health; and two, my place as an outsider coming into insider circles of research. I had started to think I might have a role in peer support as a student engaged in helping the Initiative with its mission to advance peer support in a challenging field. However, the more I learned about peer support models and about community-based and positivist research practices, my discomfort returned and I again began questioning my place and my role in the Initiative's PAR project.

While I was trying to learn more about these ideas, I was also keeping in mind the practical realities of my thesis. Time was going by and we were several months into my involvement by this point and still without a clear direction for

1 Baum et al., 2006

2 Bennett, 2004

3 Hounsell & Owens, 2005

4 Russo, 2012

31 Miyamoto & Sono, 2012

46 Denzin & Lincoln, 2018

the research. As mentioned, the research team was aware that the peer support model had not been "proven" to be effective, largely because of the debate around different research methodologies. During team meetings, the group often talked about defining "effectiveness" and now they had begun thinking about how to help peer support demonstrate that it works to achieve unique outcomes. They started thinking about creating a survey that was different from those that were already available because they were finding that existing tools were not designed to measure what the team was interested in investigating. After this development, there were several more weeks that went by with little movement toward how the team wanted to proceed. During this time, scheduled meetings were cancelled due to team members' illnesses, busyness, holidays or because the team had had a chance to talk during their work week, outside of the team meetings. This often left me in the dark about the direction of the project, and I began to feel even more uncertainty about the direction of this research and my thesis. Reaching out to ask questions outside of team meetings proved difficult too. Frequently, my emails would go unanswered for long periods of time or I would be told that team members were very busy or unavailable. The common responses I received were that they would either get back to me when they could or that they would discuss my queries at the next meeting (which were often several weeks apart). However, it was still early days into my MSW program and as a part-time student I had a few more years to complete, so I decided not to panic at the slow pace of the work at this time. I occasionally reminded the team of my need to complete an ethics

form (and the time this would take) in order to be able to move forward with the research for my MSW thesis. However, the team was making changes to their research goals often and were frequently unsure of the next steps, both of which made completing the ethics forms impossible. They began joking that this was a "developmental" process, but promised to keep in mind my needs.

I also wondered why the team seemed to be keeping me at arm's length. As a group who believed in PAR methods of partnership (which I learned from them meant including all team members in all the research steps) and who had welcomed me into their project, I was confused by their approach. I thought this might either be because they did not trust me yet or because they did not quite know how to support a student through a thesis that was stemming from their research. Thinking I could do something to address the first reason, I decided that my goal at this point in time should be to make sure that I was as helpful as I could be in order to develop my relationship with them and, perhaps, increase their sense of trust in me. My hope was that when the time came, they would feel comfortable and safe enough to include me more in their processes and allow me to do some of the "heavy" research. I busied myself with any tasks that the team asked me to do, which came mainly in the form of information finding. I had access to my university's library, which meant that I could find current articles and research on peer support and what others were doing in the field. This was helpful to the team, since their mission was to lead the way in innovative approaches in all things "peer support", and, it made me feel like I had something

to offer them. Then it happened, the day finally came when I was asked to do something substantial: to design a survey. The team had decided to develop a way to measure outcomes for people who had received peer support services. I worked quickly in order to keep this momentum going. I was hopeful that we now had a direction for both the project and my work. Within a weekend or so, I had completed the design of the survey. Unfortunately, after presenting the survey to the team, more time went by with little movement forward. This increased my anxiety and I began to seriously question if I would be able to get what I needed from this experience in order to complete my thesis.

The only real opportunity I had for contact with the team was at their meetings, so I continued to attend meetings and listen carefully to the discussions while trying to figure out what was causing the frequent changes in research directions, how the team came to their decisions, and what were the reasons for the delays. The team's discussions often referenced various barriers for the Initiative such as defining peer support worker roles, mental health professionals and policy makers' resistance to change, and translating change into effective programs. However, no attention was being given to the survey that was created or to my role in the project. It seemed to me like the team was struggling with the next steps. I was careful to gently probe the team's unresolved direction and to remind them of my ethics requirements and timeline. They responded that they never forget about me, but also informed me that they were sometimes busy with other responsibilities, and again, cited the "developmental nature" of this project.

More time went by, more meetings were held, some were cancelled, and then ... one day I showed up to a meeting and was informed that the survey I designed was no longer going to be used. The team's focus for research was going in another direction, I was told, and we were no longer exploring the efficacy of peer support. I was disappointed and frustrated by this news. Over the next while, the team continued to ask me to research various topics and ideas, which I did, along with returning to my own research into the literature about knowledge making processes and outsider roles. I was about a year and a half into my program now, and I was also plugging away at my classes. As part of the requirements for class assignments, I began writing about my experiences with the project in some of my term papers. Many of the classes in my program were centered around our thesis project, with the intent of helping us complete all the required aspects as we moved through the program. I checked in with the research team to see what kind of information and data they were comfortable with me sharing and using for my own purposes. This discussion led to what I would be able to use for the thesis itself and that brought on the issue of intellectual property rights, which became a concern for some members of the team. Their decision was to discuss it privately and draw up a contract for me to sign. A contract never materialized, but another concern came up for me. Once I had begun submitting material for my classes and talking about it in class discussions, some of my professors began worrying about my situation and suggested that I connect with a thesis supervisor. There is no protocol or guide available at my

school for the kind of project I was taking part in, and I was holding off finding a supervisor thinking this was something that I needed to do only when I had a clearer direction for my thesis. In hindsight, this was something that I should have done much sooner.

Two significant events happened once I connected with my thesis supervisor. One was my supervisor's warning about the lack of an approved ethics protocol for the Initiative's project and the implications that this would have on what I would be able to use for my thesis. She also asked me to inform the research team that I would not be able to work with any research participants until I had ethics approval from my university's ethics board. This created several more difficulties for me. I was unable to complete the ethics forms because these required a layout of the research, which the team did not have. And, once the team did decide on the next steps in their project, I was not informed or involved in some of their data gathering activities. This was because the team had begun to feel that their window to be leaders in knowledge creation within peer support was closing and so began to move fast. It was also because some of their activities involved human participants. Since I had informed them that I would not be able to engage with participants without ethics approval, and this approval takes weeks, they went ahead with parts of the project without me. The conflicts of intellectual property rights and ethics procedures within the university versus the Initiative's way of doing things incited me to find out more about the processes of knowledge creation for peer support and academic settings and my role in both of

these. I did this by expanding my course study to undertake an independent studies course which allows students to focus on a topic of interest.

What happened next: More changes, delays and learning

One of the options that I had to fulfill the course requirements of my degree was to take a directed readings course. This course is a concentrated study of the literature designed by the student -in consultation with a faculty member supervisor- of an area of interest in social welfare policy and/or social work practice, typically an area of relevance to the student's research thesis. I thought this was a perfect opportunity to get a credit and learn more about some of the issues that I was still wrestling with. My thesis supervisor agreed to be my professor for this one-on-one course, and we called it "Critical and Transformative Research and Evaluation: Participatory Action Research". This gave me a chance to explore the critical research and evaluation methodologies and methods associated with PAR and connect it to what was happening for the Initiative. I wanted to know more about how to conceptualize and conduct PAR and how this approach calls into question mainstream research methods, knowledge production and evaluation processes. I set out to explore the tensions, challenges and possibilities of PAR as well as develop skills in action research design and managing the participatory research process.

I started meeting with my thesis supervisor regularly, both for my directed readings class and to touch base about my thesis. As far as the delays and obstacles for the research project went, we decided that I still had the opportunity

to wait and see if this project would continue within the time that I had left to complete my program. I was in somewhat of a precarious position now, but I was still committed to the research team and their cause. Moreover, I had invested so much time and effort that I wanted to leave them (and myself) with something tangible that we could both use for our own gains. The team was doing important work promoting and pushing forward peer support, and I was committed to helping. I just felt more unsure than ever of where I fit it, and how everything was going to work out. All I could do in the meantime though was continue with my studies.

In my further investigations into PAR, I began to learn more about why peer support was having such a difficult time providing proof of its effectiveness. I also wanted to learn more about how and when researchers should or should not do their work when their goals are justice-oriented knowledge production and the reconceptualization of mental health services within a framework of social justice. Turning back to the literature, I began learning that even though there have been shifts in knowledge creation towards participatory methods as a way to respond to global concerns that have to do with rights and voice, community development perspectives, and developments in qualitative inquiry,⁴⁷ knowledge that is the result of current conventions in the world of science still reigns supreme.⁴⁸ The philosophical assumptions that ground any research project contain a particular

⁴⁷ Nind, 2011

⁴⁸ Vasilachis de Gialdino, 2011

stance towards the nature of reality (ontology) (for example, universal or particular) and the nature of knowledge (epistemology) (for example, objectivism or subjectivism),⁴⁹ each of which come with beliefs, biases and practices that continue to be related to the perceived quality of research findings. Added to this are the present-day neoliberal beliefs and discourses that push evidence-based research practices and methodological conservatism based on "scientific ways" which work to devalue critical, qualitative, transformative research meant to help people to struggle and resist oppression and challenge current forms of inequity and injustice.⁴⁶

I learned that PAR is different from other approaches to health research because it is political in nature and is based on methods and practices that work towards improving health, reducing inequities and finding meaningful solutions. Unlike PAR, traditional scientific methods: are grounded in a positivist framework, claims of neutrality and objectivity, and usually unexamined and accepted ways of knowing and doing. They aim to make time and context free generalizations; are often oppressive and exploitative of marginalized groups; can be insufficient in providing the information needed to achieve social justice; and are often unable to produce relevant solutions and follow-through action for the community. In contrast, PAR is explicit about its underlying assumptions, values and goals, and has at its roots a critical stance aimed at social justice and action

⁴⁶ Denzin & Lincoln, 2018

⁴⁹ Crotty, 1998

that is accomplished through reflexive, collaborative methods that consider social and historical context, power and an interpretive paradigm. It questions the nature of knowledge and whose interests it serves, and also asserts that experience is a legitimate source of knowledge. Privileging experience not only brings to light the unique insights of a marginalized group's experience that cannot be discovered through traditional research methods, it is also helpful in practical matters like the design of the research project because participants know which procedures and questions are able to get to the heart of the issue and which are likely to cause them distress.¹⁻⁴ Overall then, PAR focuses on knowledge production, research processes which are collective and democratic, and action. In other words, PAR offers a "radical alternative to knowledge development ... for the purpose of improving a situation".⁵⁰

It is important for me to note that while positivist research is generally associated with quantitative methods and interpretive research with qualitative ones, PAR is not necessarily about one method or the other. It is about how you approach whichever method you are attempting to use to get at the information that might best help in realizing the end goals of the community. In contrast with a few decades ago, when medical/positivist methods were regarded as the only acceptable standard in public health research, many authors now agree that

¹ Baum et al., 2006

² Bennett, 2004

³ Hounsell & Owens, 2005

⁴ Russo, 2012

⁵⁰ MacDonald, 2012, p. 37

effective public health research requires a combination of methods. While PAR draws on the paradigms of critical theory and interpretivism, it may use a range of qualitative and quantitative methods.¹ This helped me to understand and accept why the team was using methods like a survey which incorporated both qualitative and quantitative elements to gather information. This was something that I had questioned along the course of this project because I initially associated PAR with strictly qualitative methods, but now began understanding that a combination of methods can be used to gather data, depending on the needs of the situation.

So far, this information explained to me (to some degree) why the Initiative was using PAR, but it did not fully explain all the questions I had about this project. I found it necessary to continue to investigate and connect all the dots. Expanding and understanding the concepts from above and discussing further how PAR differs from conventional research turned out to be essential for understanding why this approach was so important for this research team. It also helped explain why some of the things turned out the way they did for me and the team, and helped me to accept my place in this work. Because of this, I will once again tell you about what the literature has to say and how it helped me to clarify and connect what was happening for me and the team.

One of the things that PAR does differently is focusing on research whose purpose is to enable action. Action is achieved through a reflective cycle, whereby

¹ Baum et al., 2006

participants collect and analyze data, then determine what action should follow. The resulting action is then further researched and an iterative reflective cycle perpetuates data collection, reflection, and action.^{1,50,51} This helped explain to me the constant courses of discussions that the team was having about what and how to research, and the following investigations into the problems that came up and changes that occurred after each course. The team had a very broad goal in the beginning: to help advance peer support, but they were in uncharted territory which required constant exploration, reevaluation and refinement as certain pieces of information began to surface throughout their research process (more on these changes in focus will be chronicled later).

A second difference that I learned is that PAR pays careful attention to power relationships, advocating for power to be deliberately shared between all members of the project: it is crucially important that power be shared between the researcher and the researched. This way, the researched cease to be objects and become partners in the whole research process; from selecting the research topic and questions, to data collection and analysis, to deciding what action should happen as a result of the research findings and then initiating that action. Most health research involves people as passive participants whereas PAR advocates that those being researched should be involved in the process actively.^{1,50,51} As consumers/survivors, this aspect is essential for the Initiative's research. Not only

¹ Baum et al., 2006

⁵⁰ MacDonald, 2012

⁵¹ Elliott, 2011

do the core team members have experience with mental health and substance problems, but the framework that they would choose later on to carry out the next stages of research would include other members of the Initiative and other people within the community, all of whom have lived experience in these areas. What was still unclear to me was why, despite having been invited to join the project, I was not being included more in the process. I understood that I did not spend as much time with the team as they did with each other and that this would inevitably leave me out of many of the ongoings as they happened. But, based on principles of PAR alone and peer support additionally (not to mention fulfilling the obligations of having a student), I would have assumed that more of an effort would be made to treat me as an equal member of the team. It would have made the entire process easier for me to understand and navigate if I was provided with more information and included more in the team's activities and decisions. This would have made me feel more a part of everything, helped to ease some of my anxieties and possibly helped me to make some decisions about my thesis earlier. As it was, the situation caused me to continually question my acceptance by this group, struggle to find a direction for my thesis and worry about completing it in general.

Third, PAR differs significantly from traditional or positivist science in a number of ways. One of which is how positivists see the world as having a single reality that can be independently observed and measured by objective scientists preferably under laboratory conditions where all variables can be controlled and

manipulated to determine causal connections. On the other hand, PAR believes in multiple realities and suggests that the observer has an impact on the phenomena being observed and brings to their inquiry a set of values that will inevitably influence the study. PAR also contrasts with traditional approaches that remove data and information from their contexts and, instead, explores issues by examining the information and circumstances that form the setting around the issue being examined.¹ Moreover, this paradigm allows for different perspectives to be included, which addresses tensions identified by some authors around whose voices should be included in research or which interpretation should take precedence.^{52a} Rather than obscuring differences, more inclusive research strategies such as PAR enable "voices to more easily stand alongside each other, and when necessary be explicitly owned by different members of the research group".^{52b}

For me, these points are key because they expose the battle that the Initiative and peer support was mired in as they attempted to convince those that have the power to make this service available to anyone who could potentially benefit from it of its worth. From what I was learning from team discussions and my readings, the problem appeared to be that quantitative methods and medical priorities (like reducing symptoms and hospital stays) seem to be more important

¹ Baum et al., 2006

⁵² Bigby, Frawley & Ramcharan, 2014a (a)

⁵² Bigby et al., 2014a, p. 62 (b)

to policy makers and most medical professionals than social justice issues like quality of life and equity and equality.^{5,40} Alternative perspectives, qualitative methods that value lived experience and more holistic objectives were not being considered, even if they also achieved some of the same results in terms of reducing symptoms and hospitalizations in addition to positive effects on quality of life, satisfaction with services, and other outcomes specifically relating to a recovery process (i.e., self-rated recovery, hope and empowerment).^{20,40}

Besides trying to unravel why there was so much uncertainty and fluctuation in what the Initiative's research would focus on, I wanted to understand how to reconcile the tensions around knowledge making for peer support and to also attempt to resolve my uneasiness around having a part in it, all of which appeared to tie into one another. Turning back to my readings, they were able to explain to me how to fit the pieces together. As was the case for peer support, the literature was stressing that it is critical to understand that PAR's values and methods developed from conditions of inequality and oppression which grew into a political stance with social transformation objectives.⁵¹ Decades ago, conditions that excluded certain groups in society from creating and participating in their own way of thinking, feeling and acting prompted liberationists like Orlando Fals Borda and Paulo Freire to establish new ways of doing research that "combined social investigation, education and action

⁵ Shannon, 2013

²⁰ Cyr et al., 2016

⁴⁰ Lloyd-Evans et al., 2014

⁵¹ Elliott, 2011

in an interrelated process".^{51,53a} In the second half of the twentieth century, PAR grew and took hold in the global south where the idea of collectivity was still an accepted way of doing and being.⁵¹ Proving to be adaptive to different settings and problems, PAR has migrated around the globe as an alternative to top-down projects that devalue local knowledge and experience,⁵¹ and has expanded around the world in networks of non-governmental organizations in the last few decades.^{53b} This approach's emancipatory goals, which developed from socialist and feminist concepts like empowerment and participatory democracy, are the foundational elements of PAR methodology which takes a critical, collective, subjective and equality-based view to knowledge development.⁵¹ And, while there are many approaches to PAR and it has been used in multiple ways and for different purposes,^{51,54,55} its goal of realigning power relationships through "democratizing forms of context-specific knowledge creation" techniques,⁵⁶ fundamental principles of equality and social change, and shared ontological and epistemological views, have in common certain themes and recommended practices.⁵¹

Even with common themes and practices, I was finding that conceptualizing PAR (and how to do it) can be a difficult task. Often described more as a philosophic orientation to research rather than a theory or a particular

⁵¹ Elliott, 2011

⁵³ Hall, 2005, p.5 (a)

⁵³ Hall, 2005 (b)

⁵⁴ Franco, 2005

⁵⁵ Stoecker, 1999

⁵⁶ Greenwood, 2008, p.329

set of methods,^{51,57} there are many definitions and ways PAR can be carried out.^{50,51,57} However, there is more convergence than divergence among participatory projects.^{50,51} PAR is principally about disrupting mainstream methodologies by producing a different knowledge base (epistemology),⁵⁸ and is unique in that it pays as much attention to the research process as it does to its outcomes in order to achieve its fundamental goals.⁵¹ Commonalties include: meaningful consumer involvement in all phases of the research process; power sharing between researchers and consumers; mutual respect for the different knowledges that all the team members have; bidirectional education of researchers and consumers; using the results of research to create new policy, program, or social initiatives; and an understanding of participants as active subjects (versus passive objects) in the research.⁵⁰ Although there is no prescribed/single method, there is agreement that PAR should be: flexible and adaptable^{52,59}; and requires a continuous process of reflection and adjustment between all members of the project.⁵² Similarly, change is defined as: (a) the development of critical consciousness of the researcher and participants; (b) improvement in the lives of those participating in the research process; and (c) transformation of societal structures and relationships.⁵⁰

Ideally then, PAR practices can involve both researchers and participants

⁵⁰ MacDonald, 2012

⁵¹ Elliott, 2011

⁵² Bigby et al., 2014a

⁵⁷ White, Suchowierska & Campbell, 2004

⁵⁸ Rose, 2017

⁵⁹ Mjøsund et al., 2017

throughout all stages of the research project from defining the research questions to the dissemination and action stages.^{2,50,51,57} Power is shared between all team members which is meant to work towards eliminating the inequality that typically occurs with researchers and participants in a traditional research design. All team members participate in making collaborative decisions and everyone is considered to have unique and equally important contributions that create mutual learning. Participants are regarded as experts due to their lived experiences related to the research topic and there is a mutual respect among all team members regarding their unique areas of expertise. By involving participants in the research process, PAR promotes meaningful changes that are desired by the group in the form of policy, program or research developments with the overall goal being to use research findings to influence social change.^{2,50,51,57} Accomplishing this requires an iterative process that is reflexive, transparent and responsive to whatever situations arise.^{59,60} The point is to create a process of knowledge production that attempts to counter traditional research paradigms that exploit people, exclude first-person knowledge, and, as in the case of mental health, work to reverse the types of treatment people received as users of mental health services by promoting choice and the rights and self-determination of those living with a

² Bennett, 2004

⁵⁰ MacDonald, 2012

⁵¹ Elliott, 2011

⁵⁷ White et al., 2004

⁵⁹ Mjøsund et al., 2017

⁶⁰ Evans et al., 2012

mental illness.^{2,4}

This is when I really began to see and think through the discrepancies between PAR practices and how I was being involved/treated by the team. Although I kept trying to insert myself into the research and continued to be helpful, the team continued to leave me out in the periphery of their work instead of including me more. When I brought this up with the team and wanted to know more about what they were doing, I was told that it was work that did not concern me. I again started to wonder whether this was because of my outsider status (even if this was unconsciously being acted out by the team), or if the team just did not know how to support a student, or both? What I needed to know more about was my place in this team's project, at least in terms of what the literature had to say. What I discovered from the literature is that there is a range of methods and a spectrum of accepted levels in terms of participant control as well as a continuum of accepted levels of participation for both insiders and outsiders.

While PAR emphasizes participation and action in the research process with the goal being to collectively understand the problem and address the issues that are important for all members, opinions around involvement range. On the one end, there are authors who argue that "any meaningful attempt to progress along a continuum of participation should be recognized and encouraged".⁶¹ Other authors argue for collaborations between insiders and outsiders based on each

² Bennett, 2004

⁴ Russo, 2012

⁶¹ Southby, 2017, p. 128

person's skills, expertise and knowledge^{52,62} while some also encourage increasingly shifting power and control over to the community.⁵⁵ At the opposite end are those authors who argue for "the most extended development" of PAR (called user/survivor-controlled research), enlarging the role of participants in the research process into areas traditionally done by researchers with the aim of eventually eliminating them altogether.^{4,51,63} However, even in user-led or user-controlled research projects, some authors suggest that service users do not necessarily need or want to undertake every stage of the research and that "professional" researchers need not be excluded from the process altogether.³

The answer to what kind of PAR and what involvement and role an academic researcher should have remains a complicated one and seems to depend on many factors. This may be even more the case for a junior researcher like me. The Initiative's research project fell on the user-controlled end of the spectrum, but they did initiate relationships with outside consultants and researchers when their expertise, resources and/or skills were needed. The information that I was discovering up to this point helped me to begin understanding why I might have been brought into the project, but I was still unclear about how the Initiative understood my role and why, if there was space for different roles, was I being

³ Hounsell & Owens, 2005

⁴ Russo, 2012

⁵¹ Elliott, 2011

⁵² Bigby et al., 2014a

⁵⁵ Stoecker, 1999

⁶² Tregaskis & Goodley, 2005

⁶³ Goto, 2010

shut out? I continued to search the literature for answers.

What I found was that there is agreement in the literature around general categories of roles and acceptable reasons for an insider and outsider to become involved with a participatory action project, at least in the beginning of the project. Sometimes labeled differently, typically roles and levels are often described as consultative (limited involvement), collaborative (weaving features of user-focused research into mainstream work), and user-led (control/own all processes).^{64,65} Some writers go further and categorize academics' roles as initiators, animators, organizers and educators.⁵⁵ Variations in involvement seem to be explained by: the need for or lack of various skills needed to conduct research or get certain results/answers⁵⁷; who is doing the research and their capability to do PAR within certain environmental restrictions, such as academia⁶¹; which group is conducting the research and their ability to carry out all phases of the project (like, for example, people with cognitive disabilities)⁵²; and the community's stand on the involvement of outsiders and the potential for researchers to impose their perspective and silence the voices of the marginalized group.⁴ Many more authors support the idea of collaboration between researchers and consumers but caution that different roles and activities should be assigned in

⁴ Russo, 2012

⁵² Bigby et al., 2014a

⁵⁵ Stoecker, 1999

⁵⁷ White et al., 2004

⁶¹ Southby, 2017

⁶⁴ Gupta & Roberts, 2014

⁶⁵ Rose, 2003

a way that honours PAR philosophy and facilitates achievement of the intended research outcomes (i.e., assigning roles according to expertise).⁵⁷ Others recommend that insiders involve outsiders in their projects because collaboration helps service users to access university resources like funding and library resources, and/or gain different knowledge and skills to explore issues, which allows for maximum advantage of resources and everyone's unique skills, "rather than wasting resources on teaching skills that duplicate or mimic those of academics".⁵²

Nevertheless, the approaches and roles available to academics seem to remain full of tensions. "The problem, however, is not with the approaches but with a conception that PAR is a research project. It isn't. It is a community organizing and/or development project of which the research is only one piece".⁵⁵ The literature explained that an organizing and development project has three goals: learning knowledge and skills relevant to the task at hand; developing relationships of solidarity; and engaging in action that gains victories and builds self-sufficiency. Doing research is not, in and of itself, a goal - the research is only a method to achieve these broader goals. Researchers should understand that this may be where their discomfort lies and that in real social change, the researcher does have a role, and the role is only one of many. What needs to be considered are the roles and skills needed for a successful outcome. For this, the

⁵² Bigby et al., 2014a, p. 62

⁵⁵ Stoecker, 1999, p. 845

⁵⁷ White et al., 2004

key questions to ask when entering a PAR project should be: 1. what is the project trying to do? 2. what are the academic's skills? and 3. how much participation does the community need or want?⁵⁵ Overall, researchers can typically contribute by examining the processes and providing technical skills and assistance with the research project.⁶³ However, methodology and methods should be able to bridge participant and academic needs, priorities and agendas.⁶⁶

It was at this point in my learning that I began to feel like I did indeed have a place in the Initiative's research project. Referring back to the learning that had taken place in my undergraduate classes which seemed to limit the roles that an outsider should play in research with marginalized groups, I now understood that there could be space for an outsider depending on the specific research context and the needs and wants of the community. My initial discomfort came from not recognizing this and not trusting that the Initiative did see value in my participation. Moreover, my readings suggested that having research teams with diverse identities can be an advantage, provided that researchers reflect upon the identities and status sets that they bring to a research project along with the ways in which these may affect the research process and its outcomes. The key is maximizing the advantages and making the most of having an outsider on a research team while minimizing the risks by attending to power and privilege differentials between team members.⁶⁷ Although I was not able to sort out from

⁵⁵ Stoecker, 1999

⁶³ Goto, 2010

⁶⁶ Bigby, Frawley & Ramcharan, 2014b

⁶⁷ Kerstetter, 2012

the literature exactly why the Initiative kept me at arm's length, I continued to think about it and try to make connections as I was learning from the literature. I did, however, now feel like I had a better handle on peer support, PAR and insider/outsider roles in general. What I wanted to know more about was how all these things connected to knowledge creation processes and the challenges and barriers that the Initiative was working against in their efforts to promote peer support, as well as to my struggle to complete my thesis. I continued to dig deeper into the literature and began to focus on connecting all of these ideas together.

The literature notes that there are differences in perspectives around what is understood to be the advantage of having user involvement in research (i.e., the creation of knowledge): one advantage from the perspective of professionals is that it leads to delivering better and more responsive services whereas users also see personal benefits that are life enhancing in general, like social interaction, confidence, self-esteem, etc.⁶⁸ However, there is agreement around the potential for the development of relevant research questions; promoting reliable and relevant research approaches; ensuring the outcomes are contextualized; and enhancing dissemination.^{50, 51,63,64, 69-71} Furthermore, there is consensus that the benefits for participants include: empowerment, building capacity and self-

⁵⁰ MacDonald, 2012

⁵¹ Elliott, 2011

⁶³ Goto, 2010

⁶⁴ Gupta & Roberts, 2014

⁶⁸ Omeni, Barnes, MacDonald, Crawford & Rose, 2014

⁶⁹ Borg, Karlsson, Kim & McCormack, 2012

⁷⁰ Grieb, Eder, Smith, Calhoun & Tandon, 2015

⁷¹ Lushey & Munro, 2015

determination; increased self-esteem, confidence, and social inclusion; minimizing power imbalances; increased critical awareness and learning (for all team members); gaining skills; reducing stigma; liberating, equitable and life enhancing effects that help rebuild peoples' capacity to participate in the social world and make meaningful decisions; and finding meaningful solutions and improving practices, services and policies.^{50,51,61-64,68,69-71}

I learned as well, that despite the positives, PAR comes with many challenges and cautions. My experience with the Initiative's project confirmed the literature's overall description of PAR as time consuming and requiring increased funding in terms of resources like training, support and remuneration for all team members.^{1,50,59,72} It can be experienced as an additional burden to an already heavy workload for researchers and an extra burden for participants who may be overloaded already and struggling to provide for the basics of life.^{59,72} Another concern is that it can be difficult for others to replicate.⁵⁹ Other difficulties include: divergences of perspectives and values between team members; lack of agreement around the direction or purpose of the research; not everyone being

¹ Baum et al., 2006

⁵⁰ MacDonald, 2012

⁵¹ Elliott, 2011

⁵⁹ Mjøsund et al., 2017

⁶¹ Southby, 2017

⁶² Tregaskis & Goodley, 2005

⁶³ Goto, 2010

⁶⁴ Gupta & Roberts, 2014

⁶⁸ Omeni et al., 2014

⁶⁹ Borg et al., 2012

⁷⁰ Grieb et al., 2015

⁷¹ Lushey & Munro, 2015

⁷² Chen, Diaz, Lucas & Rosenthal, 2010

heard or represented; the ability to manage different priorities and deadlines; issues of power and control over the project and ownership of the data; negative impacts on co-researchers and participants; and problems of tokenism and co-optation.^{4,50,59,63,71} In addition, discrimination and stigma persist for service users who are often seen as junior researchers or consultants with little or no monetary compensation given for their contributions.⁴ Further, many professionals and academics are still skeptical about the value of user involvement, and power differentials remain, even if the user researcher has all the requisite degrees which is reflected in their perceived lower status and salaries.⁶⁵

For me, this is the point in my studies where the conflict between peer support, PAR and traditional styles of doing health research really started to tie into, and overlap with, knowledge creation. I was finding that many authors give warnings about the competing agendas and different research priorities that academic researchers and community members often have. For example, differences in research priorities between professional/academic and user-led research frequently centre around users putting emphasis on social instead of biomedical interventions, on the quality of services, and the development of alternative/complimentary services and therapies (i.e., a holistic approach that is

⁴ Russo, 2012

⁵⁰ MacDonald, 2012

⁵⁹ Mjøsund et al., 2017

⁶³ Goto, 2010

⁶⁵ Rose, 2003

⁷¹ Lushey & Munro, 2015

biomedical, social and psychological).⁷³ Further, professionals and their affiliated organizations and funders often want to hold onto their power and promote their interests by maintaining the status quo, while users pursue innovation and research methods that promote liberation and well-being.⁴ Competing agendas in knowledge production are also, in many cases, about users wanting translational research intended to adapt findings for clinical use, whereas researchers tend towards discovery or academic curiosity.^{3,51,73} Additionally, researchers typically gain more than community members in terms of who contributes and risks what, with researchers acquiring knowledge, career advancements, getting published, etc.,⁵¹ whereas community members may contribute equally but gain nothing and risk physical, psychological, social or economic harm.^{59,71,74,75} The good news, I found, is that the literature offers ways to mitigate these concerns. Building bridges between academia and the community involved³ and ensuring that the outsider remains in service (and is accountable) to the community -instead of the typical accountability that lies with the researcher's institution, supervisor, funders, etc.- can work to lessen the impact of these imbalances and issues.⁵¹

This all seemed to be connectable to what was happening for the Initiative and for me. The Initiative's priority was their research, which could have been one

³ Hounsell & Owens, 2005

⁴ Russo, 2012

⁵¹ Elliott, 2011

⁵⁹ Mjøsund et al., 2017

⁷¹ Lushey & Munro, 2015

⁷³ Robotham et al., 2016

⁷⁴ Löfman, Pelkonen & Pietilä, 2004

⁷⁵ Stuart, 1998

of the reasons why my student agenda and priorities were often not treated as a first concern. Their ultimate mission was to find ways to push forward their interests, and mine was to complete my degree. The Initiative's objective of trying to bridge professional mental health agendas and notions of wellness with the social justice and holistic interventions that are associated with peer support was a complicated one. It was also becoming clear to them that timelines for this were getting shorter and shorter as other peer organizations were closing in with similar ideas. For the research team, this must have felt like it necessitated working outside of traditional knowledge making processes, whereas my goals required time and following university customs associated with producing knowledge. Additionally, three sets of competing agendas with the Initiative stuck in the middle could have made them feel like they had to choose their own goals over mine, particularly if they did not have the know-how required to also balance my needs. While none of these revelations were particularly good news for me, what I did feel good about was my continued commitment to the team's research agenda and needs. This was in keeping with what the literature recommended in order to stay in service and accountable to the Initiative.⁵¹

Continuing with my studies, I was learning that in terms of participants/the community having full control over the research, some experts wonder whether it is really necessary or even possible to achieve, particularly with some groups that

⁵¹ Elliott, 2011

require support (like children or people with cognitive disabilities).⁵² Furthermore, although PAR attempts to equalize power⁴ and includes power diminishing activities and actions that can be "undertaken to narrow the gap between control held by professionals and by consumers, it might not be possible to close that gap completely".⁵⁷ To manage and reduce power issues, the advice from the literature is to be transparent about the researcher's standpoints, motives and identity.^{4, 58} Certain authors further promote developing and maintaining a closeness to subjects,⁵⁸ and ask that "professionals and consumers engage in the previously mentioned activities [of PAR] to approximate equality to the highest degree feasible".⁵⁷ Yet, it is important to mention that some believe that if outsiders are involved, then empowerment can never be fully achieved by the participants.⁴ However, if an outsider does decide to be involved in a PAR project and the community has asked for their help, the recommendations are to know your skills and your limits,⁵⁵ and know your place in the areas of power, knowledge and accountability.⁵¹ This point is particularly relevant to my situation. It was important for me to understand my place in the Initiative's project, and to reflect upon my skills, limits, power, etc. I also believe that the Initiative understood and considered all of this about my role on some level. They must have believed that my lack of lived experience would be mitigated by what I

⁴ Russo, 2012

⁵¹ Elliott, 2011

⁵² Bigby et al., 2014a

⁵⁵ Stoecker, 1999

⁵⁷ White et al., 2004, p. 8

⁵⁸ Rose, 2017

could bring to the project. Moreover, some authors argue that even user-controlled research does not have to mean that service users undertake every stage of the research, or that professional researchers are necessarily excluded from the process altogether.³ It does mean that service users initiate the research, direct its course, and ultimately own the findings.³ Contracting researchers as needed appears to be the best way to navigate this issue, with the point being to combine the knowledges of the insiders and outsiders in order to achieve the desired outcomes.⁵¹

I also discovered that other problems have been documented in PAR beyond the issues of power relationships, accountability, roles that academic researchers play, and ownership. One of the biggest criticisms of PAR centers around ideas of research validity, reliability and rigour and the perception that there is a general lack of quality in the PAR data that is produced.⁵² Complaints and observations related to these areas have some authors discussing its subjectivity, lack of generalizability^{52,76} and potential to "become trapped in a cycle of sentimental biography and individual anecdotes".⁷⁷ Others contest the privileging and separation of expert knowledge from experiential knowledge; express frustration at the complexity and inaccessibility of research methodologies; and/or criticize the scarcity of attempts to include the researched

³ Hounsell & Owens, 2005

⁵¹ Elliott, 2011

⁵² Bigby et al., 2014a

⁷⁶ Ercikan & Roth, 2016

⁷⁷ Walmsley, 2004, p. 65

in every phase of the research process.⁷⁸ Fortunately, researchers have started to respond to these challenges,⁷⁸ and authors are increasingly discussing in detail what counts as evidence, whose knowledge matters and what processes and methods to use to get at it. Contemporary scholars talk about how traditional research can (still) often be: something that is done by people in universities or research institutes for their own interest; theoretical rather than practical; and not really about helping people to address concerns that are important to them.⁶⁹ Good research, they suggest, is not just about publishing books and academic papers, it is also about the creative actions of people to address matters that are important to them, and revisioning how we understand our world, as well as transforming practices within it.⁶⁹

The idea of knowledge as power was first taken up by Freire.² Freire and other likeminded thinkers see power and knowledge and their operations as inseparably related because knowledge is always an exercise of power and power is always a function of knowledge. The literature in favour of alternative ways of knowing and doing continues to challenge accepted ideas of what counts as knowledge and who has the power to say what that is. For example, there are scholars that talk about how power and evidence are linked together. They argue that power dynamics and structures are woven throughout processes of creating

² Bennett, 2004

⁶⁹ Borg et al., 2012

⁷⁸ Byrne, Canavan & Millar, 2009

information and the policies and practices based on that knowledge.^{79a,80} An awareness of this is critical because power influences the role of evidence and:

sometimes groups in power will insist that advocates for change must meet a standard of evidence that is difficult to achieve and higher than usually demanded in policy circles. The origin of this demand may be not a commitment to rigorous science but an effort to derail policy change.^{79b}

Despite this, limited attention is given to the processes of constructing knowledge in healthcare.⁶⁹ Who is involved in the knowledge construction, with what objectives, and for which audience or group of people, are rarely examined.⁶⁹

The concept of knowledge construction came up at the Initiative's research meetings and in the literature for peer support often. It was also clear from the discussions at the research meetings that the research team had frequent talks about this outside of the meetings I attended. Generally speaking, peer support does not assume medical definitions or solutions to mental health problems and instead promotes critical learning based on peer learning and experiential knowledge.²⁰ Wanting to avoid an adversarial approach, one of the challenges for the Initiative was finding ways to connect their approach to knowledge making with those that professionals from medical/positivist organizations subscribe to. Their hope was that they would be able to merge the two ways to create a new

²⁰ Cyr et al., 2016

⁶⁹ Borg et al., 2012

⁷⁹ Freudenberg & Tsui, 2014 (a)

⁷⁹ Freudenberg & Tsui, 2014, p.12 (b)

⁸⁰ Jones, Datta & Jones, 2009

understanding of what constructing knowledge in healthcare can be like. I was curious to find out more about how this can be accomplished and what others were doing to try to blend the two approaches.

I returned to the literature for some answers. What I learned started by reiterating that what counts as evidence varies and depends on methods, context and process,⁸¹ and there is a difference between traditional knowledge and its production and knowledge that is co-produced through action research.⁶⁹ Instead of placing more value on certain methods (i.e., quantitative) over others (i.e., qualitative), some scholars take a critical realist perspective on evidence and argue for ontological realism and epistemological constructivism which reject single interpretations and critique evidence-based research in important ways.⁸¹ They maintain that evidence cannot be assessed in context independent ways, but only in relation to the particular questions and purpose to which it is applied (i.e., there is no such thing as "evidence" in general). Therefore, any attempt to establish a context free hierarchy of kinds of evidence based on methods used is flawed -evidence cannot be evaluated based solely in terms of the methods used to obtain it. There is a difference between what quantitative and qualitative research seeks to achieve, and the nature of evaluation of the evidence for each of these claims are different, so, evidential standards for quantitative research cannot legitimately be applied to qualitative research. When research seeks to show

⁶⁹ Borg et al., 2012

⁸¹ Maxwell, 2009

relationships between variables, then we need quantitative methods, but if what we are looking for are relationships between events and process (i.e., interpretive claims about "what is happening", which includes participant meanings, intentions, beliefs and perspectives), this is where qualitative methods come in.⁸¹ The trick is to appreciate what both have to offer and understand that they can work together to improve and deepen the information that we seek.^{59,62}

Also, traditional forms of knowledge production make a distinction between knowledge producers and knowledge consumers which creates a "hierarchical relationship between the knowledge bearers and the knowledge users that has greatly influenced the development of knowledge in health care and has been an inherent barrier to the way that research is perceived among clinicians".⁶⁹ Proponents of this line of thinking are convinced that we have grown so accustomed to the idea of the solitary, individualistic, top-down academic procedures in knowledge creation "that we find it difficult to see the deeper ecology of creation".^{61,62,69} They believe that we need to look at how things are created and not rely solely on externally derived knowledge and forces to shape our experiences. In order to see what is around us, we need to be able to find systematic and rigorous ways of exploring and making sense of such experiences. One way of doing this is to adopt principles of PAR with the co-

⁵⁹ Mjøsund et al., 2017

⁶¹ Southby, 2017

⁶² Tregaskis & Goodley, 2005

⁶⁹ Borg et al., 2012, para. 35

⁸¹ Maxwell, 2009

creation of research agendas that focus on the everyday experiences of service users and clinicians using systematic processes of inquiry. These participatory and facilitated processes can lead to the co-production of knowledge and to a reduction in the reliance on externally derived knowledge in order to shape and re-shape experiences as the basis for knowledge construction. Collaboration between the academy/professionals and lived experience allows for understanding and learning from all experiences.^{9,61,62,69,76}

All of this information that I gathered and processed allowed me to substantiate some of the difficulties that both the research team and I were experiencing and put my mind at ease with respect to my involvement in this project. My status as an outsider and student with no experience of the problem or the practicalities of research itself did not preclude me from participating in this project. What I had to offer was the time, free labour, basic research skills and knowledge gained from my undergraduate and graduate studies, and university resources that the research team could use to their advantage. I also maintained my commitment and accountability to the team and their goals which helped me to accept that my lack of lived experience and the issues associated with this were minimized. The reality of the time involved in this kind of work, both as a developmental/emergent process of trying to figure out how to measure peer

⁹ Stringer, 2014

⁶¹ Southby, 2017

⁶² Tregaskis & Goodley, 2005

⁶⁹ Borg et al., 2012

⁷⁶ Ercikan & Roth, 2016

support's effectiveness in order to lobby for it within the healthcare system, and the repeated cycles that PAR requires was being corroborated for me in the literature. The changes, length of time, uncertainty and fight for recognition that peer support was going through (and by extension the work of the Initiative) was all part of the approach. Peer support organizations, like the Initiative, are facing the challenges of coming up with a way to bridge methodological divisions in order to have their knowledge recognized and reach their end action goals of beneficial social change. Going through this process of learning and finding out what was happening and where I stand helped me to move forward with the research project itself, and to begin to concentrate on solutions that would enable me to complete my thesis.

In the end: How everything was resolved

As I mentioned before, while I was grappling with all of the above issues, the research team and the Initiative itself had been wrestling with the complexities of providing holistic, recovery based, justice-oriented approaches within the traditional health system. The Initiative had also been struggling with certain issues that were coming up for them time and time again in their numerous efforts to advance peer support. In their attempts to understand what was happening (and unbeknownst to me until later -I am assuming because this was not specifically associated with the research project until the team started to connect this issue to the research project issues and so, as with most things, the team decided not to mention this work to me until it happened to come up at one of the research

meetings) the team had begun to investigate these barriers by engaging people at various levels of peer support provision in discussions, ranging from peer support workers to their supervisors and the organizations/institutions that offer this service. What started to emerge from their efforts suggested that there is great complexity in what peer support workers are doing and in how they are doing it. Service providers throughout the mental health system had unique and diverse expectations about roles and responsibilities for their peer support positions.

To address this issue, the research team had undertaken a formal Quality Improvement (QI) process to identify the root causes of this lack of role clarity using a wide variety of QI tools and processes. The QI processes allowed them to come to an agreement that the root cause of the recurring issue of lack of clarity in the definition of peer support roles is that peer support is values-based. What was not known is whether these values were currently and consistently employed in peer support practice when peer support was being integrated into mainstream mental health and addictions health services. The team recognized that this was something that required further attention and this shifted the research questions and direction for the team once again. The Initiative's research project now became a kind of program evaluation project. However, before the Initiative's peer support program's effectiveness could be evaluated, there was the realization that they first need to establish what peer support workers are doing and how they are doing it. The team decided that a good place to start would be to determine whether people receiving peer services perceive this support to be in alignment

with peer support values. From here, the team additionally planned on doing similar investigations but from the perspectives of peer support workers, their supervisors and their organizations. The results would then drive additional processes in relation to elements such as training, support, organizational culture and philosophy shifts to foster values-based peer support. This, they decided, would provide a mechanism to ensure service integrity no matter the setting or the role. After which next steps could be taken to determine outcomes and efficacy. After searching for tools to evaluate whether peer support values are present in peer services, the team concluded that, once again, existing tools were not designed to measure what they wanted to know. So, they decided this was the next research step; to develop a survey that measured peer support workers' behaviours to check for consistency with peer support values. And from what they had learned during their QI process, the team decided the best way to do this was by using an experience-based co-design framework, which is one of the newest evolutions of participatory action/user-controlled research being used to bring about quality improvements in healthcare organizations.⁸²

We were now about two years into my involvement with the project and I was beginning to feel the pressure of time. The team was also beginning to feel more pressure to pick up the pace in order to remain the innovators and leaders in peer support for which they were becoming known. Once more, many of the conversations that the team was having about all of this were held outside of the

⁸² Donetto, Tsianakas & Robert, 2014

meetings that I attended and I would typically be informed of activities and decisions once they had already been made and work had started. This created additional stress for me because I still did not have a clear idea of what was happening with the project, or, therefore, what I would be doing for my thesis. This also continued to create difficulties for the completion of my ethics application.

As more time went by, the program evaluation project continued to develop and branched into multiple lines of inquiry at various system levels. As I said before, the team had begun to move quickly and often without my involvement or knowledge of the goings-on. It had been decided by the team that my role would be limited to work on the survey that was at the level of people receiving services. I was informed of their plan at one of the meetings and asked if I thought this was acceptable. I agreed, recognizing that the time I had left in my program would not allow me to get further involved at this point. What I had not known was that the team had also decided that in order to start designing the survey tool, they wanted to engage people with lived experience in order to understand how they perceived their peer support workers exhibited the values of peer support. However, because I needed to go through the formal ethics process before I could work with research participants and the team was unwilling to wait, data gathering (in the form of facilitated discussion groups) was completed within a matter of a week or two and without my participation. My part then became to take the raw data and perform a content analysis, and with the team, develop key

statements that represented behaviours which would appear on the evaluation survey (I went ahead and did this without ethics clearance because I felt that this was a good learning opportunity that I would lose out on otherwise). A happy surprise came when the team decided to include six questions from my original survey design in this new survey tool. Once completed, the team was ready to send it into the field for testing. This phase was to be my responsibility, and we finally started to work on completing my ethics application.

Things appeared to be moving forward, but then stalled again at the ethics process. We did complete and submit my ethics application to my university's social science research ethics board. It took over four weeks for my forms to be assessed and approved by the board. However, the whole process became moot because in that time the team had made some alternate decisions about where and how the testing phase of our survey would proceed. They had gone from not seeking any ethical review and approval for themselves to bypassing my ethics board in order to get what they believed was the "top" of the hierarchy: approval from a medical ethics board. Through our discussions about ethics applications, I learned that the team was feeling the demand of achieving recognition and acceptance by those professionals (primarily medical) who continue to subscribe to the superiority of traditional methods. Wanting to minimize judgments about the quality of their qualitative research, the team decided to also begin to incorporate elements of research that entered into the quantitative/positivist arena, as well as begin to align themselves with medical professionals and their ways of

doing. My university's social science ethics board, it was feared, would not garner the same respect as the medical ethics board, and it was determined that the team would forge an alliance with the local psychiatric hospital and their staff, along with their affiliated ethics board to proceed with the testing phase. This took much more time to organize and again pushed my work back.

After much discussion, I was included in the new ethics application, and was able to move forward with the testing phase. Unfortunately, I had been advised by the social science ethics board that all previous work I had done on the development of the original survey and the second survey could only be mentioned as being done as a volunteer with the Initiative. This meant that in my thesis I could only write about the most recent activities that I had taken part in (the data analysis and testing phase of the survey). In addition, the research team was concerned with the proprietary nature of this information, and ownership of the data was again emerging as an issue. Writing about the research process and data in my thesis would be perceived as "my research" and "my data", not the collective work of the research team. And in all fairness, almost all of the work and all of the ideas and innovation came from them, not me. I just helped out here and there, so it did not feel right to make my thesis about the work and discoveries being made by the team. Now I was at a complete loss as to what my thesis was going to be about. I could not write about the tool, or data collected using the tool, or how we got there, and all I had was a series of often distressing student experiences about what it was like to work with an organization trying to

do interpretive, critical, participatory action research. Additionally, as a student involved with this ongoing project for thesis purposes, I needed to figure out how and when to end my involvement in it.

My thesis supervisor and I discussed the situation at length, and we made a few decisions. First, we decided that once I finished the testing phase for the new survey, my responsibilities as a junior researcher with the Initiative would be considered complete by my university and I could let the research team know that I was "done". This was two and a half years in the making and I finally had enough for a thesis! This decision was made for a couple of reasons. Time was running out and I was approaching the last semester that I could possibly stretch out my program without paying another term's worth of fees. Furthermore, during the survey testing phase, I had to miss team meetings in order to spend that time in the field. This cut me off even more from the team and I missed out on additional important changes that the group had made. A restructuring had occurred within the team and my contact person was no longer part of the project. Finding this out through an unrelated email with another team member left me again feeling apart from the team and the restructuring left me feeling like I was no longer needed. However, having plans to continue with my education, I was hoping that I could maintain some kind of mutually beneficial relationship with the team, even though I was formally finishing my involvement with their project. In my last meeting with them, I presented the results of the testing phase (which had taken me four months to complete) and we also talked about my possible

involvement in some of their future presentations and conferences. In addition, I offered my volunteer services, should the team feel they could use them in any way. In this way, I could help them out as needed, and they could help me get into a PhD program. To date, I have not heard back from them.

Another decision my supervisor and I made was that my thesis would become a study of these experiences. Wanting to avoid any conflict with the team about the knowledge that they were creating and their desire to keep it proprietary -and now having lots to say about how we all got here- this felt like the right solution. This did, however, require a return to the literature and to leaning something new. At first, we decided that my thesis might be a case study, and so I turned to the literature and learned about case studies and wrote about it in my thesis. However, during the final stages of my thesis writing process, the professor who was my second reader suggested that my storytelling approach and the work itself was more of a narrative inquiry rather than a case study. This was because both the storytelling and narrative research perspectives draw on lived experience and how participant's stories are used. This meant that I once again went back to the literature to find out about narrative inquiry and storytelling.

I learned that narrative inquiry is a qualitative research method and is a way to understand people's lived experience over time, place and in interaction with the social environment.⁸³ These three dimensions of narrative inquiry (temporality, sociality, and place) serve as a conceptual framework,⁸³ and

⁸³ Clandinin & Connelly, 2000

attending to experience through all three dimensions simultaneously is what makes narrative inquiry different from other methods.⁸⁴ Narrative inquiry attempts to capture the whole story whereas other methods tend to communicate understandings of phenomena at certain points which often leaves out the important intervening stages. This method studies problems as forms of storytelling involving characters with both personal and social stories and can therefore reveal the social context or culture in which this construction takes place. So, just as a story can uncover and explore the complexities of characters, relationships and settings, so too can complex problems be investigated in this way.¹¹ This method, therefore, seemed better suited to what I wanted to do with this thesis.

Further, narrative inquiry also challenges the philosophy behind quantitative data-gathering and questions the idea of objective data.^{83,85} It follows the interpretive ontological perspective that human beings construct meaning or reality based on interactions with their social environments. This fits together with the ontology that PAR is grounded in. Rather than viewing the knowledge that I acquired from my experience from an objective positivist stance, my thesis adopts the philosophical underpinnings of narrative inquiry, which acknowledges human experiences are contextual, dynamic and constantly changing.⁸⁶ Narrative inquiry

¹¹ Webster & Mertova, 2007

⁸³ Clandinin & Connelly, 2000

⁸⁴ Clandinin & Huber, 2010

⁸⁵ Boje, 2001

⁸⁶ Lemley & Mitchell, 2012

uses field texts (such as journals, field notes, conversations, interviews, stories, photos, etc.) and/or life experience as the units of analysis to research and understand the way people create meaning in their lives as narratives.⁸³ And, using stories lets us make sense of an experience and can show how we have come through life's challenges having learned something.⁸⁶ This is what I hope to achieve through this thesis. However, like other academics, I was concerned that the Initiative might perceive my thesis as an unfavourable review and take it as a personal criticism.⁸⁷ To address and counter this fear, I have aimed to present a fair account of my critiques and ideas on how to make this type of experience better for future junior researchers.⁸⁷

One of the last topics that I needed to explore to complete this thesis was the experiences that other students might have had in similar situations. After much searching, and with the help of a university librarian, I was unable to find any literature that specifically discussed the processes and experiences of a master's student (particularly one without lived experience) attempting to do PAR in partnership with a community organization for a thesis. I did manage to accumulate quite a stack of articles and book chapters that discussed somewhat related undertakings in the sense that they were about PAR or attempts at PAR, but these were mostly at the PhD level with students initiating the research for their dissertations; graduate and undergraduate students who worked with

⁸³ Clandinin & Connelly, 2000

⁸⁶ Lemley & Mitchell, 2012

⁸⁷ Moore, 2004b

organizations, but not for thesis purposes; or articles about partnerships between university researchers and community organizations. However, enough similarities existed between their circumstances and mine that I feel I can offer some suggestions that align with the literature, and also provide some lessons I learned from this apparently unique situation that I found myself in.

Discussion and lessons learned

This research adventure has been a tremendous learning experience for me. I was able to go beyond the few paragraphs that were covered about action research in class, demystify the research process and experience firsthand how one group of people with lived experience search for and use their own knowledge for change. I gained practical research skills and hopefully contributed to some positive change, at least a little. I also learned that there were some things that could have been done to make this process easier for a junior researcher like me. On a personal level, one of the first steps I should have taken was to connect with an advisor,⁸⁸ instead of going on ahead independently (which is how I tend to approach most things). This would have allowed me to talk through some of my outsider concerns, maybe have a more solid plan for my thesis earlier, and would have provided me with some counsel and support through all the challenges I had begun to experience early on with the Initiative. There is no plan or outline available in my faculty that is designed to advise part-time students in these kinds of situations, and I did not realize how complicated this situation

⁸⁸ Nadimpalli, Van Devanter, Kavathe & Islam, 2016

would become. I also naively assumed that the Initiative would take on a supervisor/mentor-type role and would help me navigate the process as I went. This was not the case, and I was mostly treated as an independent, peripheral character in this situation.

As the literature warns, PAR is often full of group dynamics, and requires a great deal of time and energy.⁸⁹ Reflecting back, there were some things that I did that may have distanced me from the team and contributed to me being treated a certain way. I tried to be very open and upfront about my shortcomings and limitations right from the get go. This included letting everyone know that in addition to school, I worked several part-time jobs and this restricted my time in a huge way. Although there was not much I could have done differently in my situation, I wonder if spending more time getting to know the team would have made a difference in the way I was accepted and treated by the them. There were some events (baseball games, etc.) that I had been invited to in the beginning, which I turned down because of work. After a few attempts, the team had stopped asking. I did do my best to attend and participate in as many activities as I could (both research ones and others like birthday parties and lunches that happened on the day that I was present for meetings), but the timing and often short notice of many of the activities were not possible for me to coordinate with my work schedule. I am also guilty of not addressing some of the issues that I felt were causing me distress in an assertive enough way. This was particularly true in the

⁸⁹ Moore, 2004a

beginning of our relationship because I was afraid to cause any issues. I was coming from a place of vulnerability because I needed to pass my program, I was concerned about my reputation as I started working towards becoming an active professional, and I was hoping that some kind of employment might come out of this placement.⁹⁰

These circumstances and my "student without experience" status made me feel insecure and unequal to the other team members and very cautious about bringing up the difficulties I was having with the situation. What it probably did was leave the problems unnoticed by the team or perceived in some other way. Although I would have always remained an outsider because I am not a service user, perhaps paying more attention to establishing relationships is a responsibility that needed more emphasis in this situation. This is one lesson learned for me. Possibly, what was going on was that the team did not feel like I was making enough of an effort, and so continued to treat me like an outsider.

Aside from the group dynamics, PAR comes with many methodological and institutional obstacles.⁹¹ I faced many of the same dilemmas that other student academic researchers faced, albeit some in a different way. Reconciling different research interests, shifting research interests, defining the pace and timing of the research, how to handle the information that is generated, the formulation of research proposals, ethics processes, the time constraints and culture of the

⁹⁰ Schwartz, 2010

⁹¹ Gibbon, 2002

university system, increased workload and extra time and resources required, communication difficulties, lack of support, and the lack of courses on PAR methods are common themes in the literature.^{61,89-101}

In order to begin a research project and before actively engaging in a partnership with a community group, students must develop a research proposal with research questions, research problems and a direction for the research, and go through an ethics review process, none of which typically involve the participants.^{100,102} If students were to wait until this stage was completed in the true ways of PAR, they risk not completing their program within a reasonable time frame since early relationship building activities alone can take years.^{88,89,91} Not to mention that, for students, completing this stage is not possible without ethics approval in the first place. Moreover, coming up with research questions and performing other research related activities (like early literature reviews) within the context of doing collaborative work (where the participants have more control over the processes and outcomes of the research) while coming from an

⁶¹ Southby, 2017

⁸⁸ Nadimpalli et al., 2016

⁸⁹ Moore, 2004a

⁹⁰ Schwartz, 2010

⁹¹ Gibbon, 2002

⁹² Khobzi & Flicker, 2010

⁹³ Klocker, 2012

⁹⁴ Maguire, 1993

⁹⁵ Moss, 2009

⁹⁶ Polanyi & Cockburn, 2003

⁹⁷ Puma, Bennett, Cutforth, Tombari & Stein, 2009

⁹⁸ Seymour & Garbutt, 1998

⁹⁹ Stoecker, 2008

¹⁰⁰ van der Meulen, 2011

¹⁰¹ Willis, Peresie, Waldref & Stockmann, 2003

¹⁰² Burgess, 2006

environment (the university) that then requires the student to claim and publish this knowledge as an individual is a huge obstacle.^{89,91,100,103} This is complicated by situations where stakeholders may not be willing or able to postpone the research, or wait for the student to receive ethics approval, or complete projects within tight timelines specified by the student's department.¹⁰⁰

Beyond the time needed for relationship building, PAR projects often take many more months, if not years to complete,^{61,88,89,91,93-95} and cannot be thought of as a straightforward process with successive steps and a finite ending.^{93,104} I was lucky as a master's level student in that my thesis needed only to go through one major (or several minor) planning/acting/observing reflecting cycles to demonstrate mastery of the research methodology.¹⁰³ This let me off the hook after I had completed my share of the fieldwork, even though I had not seen the project through to its completion. Even still, this took years and, if I was a fulltime student, would have been impossible to complete within the one year timeline allotted for the program. As it was, together with writing up my work, I barely squeezed into the three year limit that is typically outlined by my school as the time available to complete an MSW part-time. Tuition costs and other

⁶¹ Southby, 2017

⁸⁸ Nadimpalli et al., 2016

⁸⁹ Moore, 2004a

⁹¹ Gibbon, 2002

⁹³ Klocker, 2012

⁹⁴ Maguire, 1993

⁹⁵ Moss, 2009

¹⁰⁰ van der Meulen, 2011

¹⁰³ Zuber-Skerritt & Perry, 2002

¹⁰⁴ McCormack, 2004

financial barriers must also be considered for those who cannot afford to stay a student for extend periods.^{93,95,100} And, contrary to the accounts and recommendations of others, for me, PAR was also not a solution to the experience of isolation and estrangement that graduate students often feel when conducting their final research projects.^{93,100}

Looking to the literature for help with all the challenges I faced has uncovered some interesting trends in what is out there. Much of the literature talks about what universities are doing wrong and how the individualistic, outcome-focused, timeline-driven academic culture clashes with the foundationally collaborative, process-focused and time-intensive principles of PAR.⁹³ Additionally, literature examining PAR from doctoral students' perspectives is sparse^{61,92,93} and master's students' perspectives are nonexistent. I was only able to find one short guide in the literature that addressed completion of a master's thesis with "nine tips for writing your master's thesis".¹⁰⁵ Regrettably, these tips are directed at an individual action research project, not one that is participatory, and they did not cover any of the processes and challenges that can come with a PAR endeavor. Yet, doing PAR as a student is not just about challenges and barriers. There are many benefits too, and it would be advantageous to have a variety of accounts of both positive and negative elements and experiences of doing PAR as

⁶¹ Southby, 2017

⁹² Khobzi & Flicker, 2010

⁹³ Klocker, 2012

⁹⁵ Moss, 2009

¹⁰⁰ van der Meulen, 2011

¹⁰⁵ Johnson, 2012

a student.⁹³ In addition to developing the real-life research products that further the work of the community or community organizations, and the immense learning and development opportunities that come from a PAR project,¹⁰⁶ there is access to resources and time saving and stress reduction potential for a student joining an existing project since you do not have to mobilize one from scratch and are working as part of a team and can therefore share the workload and responsibilities with others.⁹²⁻⁹⁴ But it seems that this way of doing a master's thesis research project has not been explored in the literature, nor planned for by universities or community organizations.

To start the process of figuring out what is needed to support students working with community agencies for research and thesis purposes, it would be valuable to have more accounts of students' experiences of conducting this kind of work. Only a small percentage of researchers have investigated conceptions of research in general, and studies about the experiences of those who undertake PAR are even harder to find.^{104,107} The student perspective brings different insights, and our experiences of PAR and its effects on us are best communicated by the students themselves.¹⁰¹ More descriptions and discussions about the processes of each unique project, how these were dealt with and how they turned

⁹² Khobzi & Flicker, 2010

⁹³ Klocker, 2012

⁹⁴ Maguire, 1993

¹⁰¹ Willis et al., 2003

¹⁰⁴ McCormack, 2004

¹⁰⁶ Stocking & Cutforth, 2006

¹⁰⁷ Lac & Fine, 2018

out would be helpful to begin to design steps and structures that would assist students to plan and execute their own future projects with fewer anxieties and pressures.^{61,93} Accounts from the perspectives of faculty from universities and the members of community organizations working with students would also help to understand, develop and coordinate these efforts. More case studies on the processes and outcomes of community-based research could show both infrastructural supports and structural constraints and how these can be developed, negotiated or implemented.⁹⁶

Some changes within the university would also be beneficial if activism and research are to be practiced together.^{93,95,106} In the university setting, research is still operationalized under particular conceptions and assumptions like linear time and processes, individual work, and full-time students.¹⁰⁴ Reviewing PAR methodology with university ethics committees and restructuring the ethics application process to accommodate the participatory aspects of PAR might be an important consideration.^{93,99,107} Regardless of how willing or flexible we might be, time issues will always remain a concern for students, but are different for part-timers. The time constraints that using PAR poses also need to be investigated so that the university system can be flexible enough for any student

⁶¹ Southby, 2017

⁹³ Klocker, 2012

⁹⁵ Moss, 2009

⁹⁶ Polanyi & Cockburn, 2003

⁹⁹ Stoecker, 2008

¹⁰⁴ McCormack, 2004

¹⁰⁶ Stocking & Cutforth, 2006

¹⁰⁷ Lac & Fine, 2018

who wishes to embark on this particular journey. Universities could look at ways of implementing a more collaborative approach to working that would allow their institution to form partnerships with organizations in a way that enables students to undertake this extremely important form of research.⁹¹ Pacing and other considerations for part-time students working with communities would be helpful for university programs to develop and make available as a guide for students (and community partners). As a social work program dedicated to understanding and transforming injustices, my program is likely to attract people like me who would be interested in learning about and conducting PAR. A short seminar or practical guide on what to expect and how and what to do might be developed for inexperienced students considering PAR for a master's thesis.⁶¹ At least, more time could be spent on this methodology in class, if not in workshops or entire course offerings dedicated to PAR, similar to the one I was able to do as an independent study course.^{91,99,101,104,106,108}

Universities could also establish structures for students who have engaged in PAR projects to meet with new students, faculty and administrators to share past experiences; create solutions and prepare for placements; and create systems

⁶¹ Southby, 2017

⁹¹ Gibbon, 2002

⁹⁹ Stoecker, 2008

¹⁰¹ Willis et al., 2003

¹⁰⁴ McCormack, 2004

¹⁰⁶ Stocking & Cutforth, 2006

¹⁰⁸ Zuber-Skerritt, 2002

for receiving mentoring and support from university and community partners.^{89,101,104,109} Universities need to have systems in place for community partners to have ongoing conversations with university partners and provide feedback that goes both ways, share what they have learned about making student engagement work, and negotiate everyone's timelines and other research requirements (like ownership of the research products) as needed.^{90-92,101,106,109,110} Additionally, it would ease the burden for students if mini-grants were made available, from either the university or from project funding, to counter some of the expenses students accrue when conducting PAR research.¹⁰⁶ In my case, the Initiative provided me with gas cards and a parking pass for the time that I was in the field, which was a big help. However, none of my other time and money expenditures were compensated for. It might have also helped me to spend less time working at one of my low paying part-time jobs and more time with the Initiative and their project.

Community organizations may not fully realize the role that students can play in supporting their work.¹⁰⁶ I also suspect that some may not fully understand, or be prepared to support students in fulfilling their responsibilities to university structures. So, educating community organizations about what students

⁸⁹ Moore, 2004a

⁹⁰ Schwartz, 2010

⁹¹ Gibbon, 2002

⁹² Khobzi & Flicker, 2010

¹⁰¹ Willis et al., 2003

¹⁰⁴ McCormack, 2004

¹⁰⁶ Stocking & Cutforth, 2006

¹⁰⁹ Stack-Cutler & Dorow, 2012

¹¹⁰ Sandy & Holland, 2006

can offer and university processes is important. Some targeted training or manuals developed by the university for community organizations could be an important step in ensuring that these agencies can reap the benefits of having students on their teams, but can also make sure that they structure their project in a way that fits students' needs and minimizes our stresses and uncertainties. Communities can engage with higher education institutions to have additional access to resources and volunteer labour; get help with their research; facilitate and increase their learning experiences; build advocacy capacity and meaningful, sustained relationships; and to raise the profile of their organization.^{88,106,111}

However, for these collaborations to be successful and consistent with PAR principles, certain considerations must be addressed and met. Strong relationships are central to successful partnerships, which means that communities need to be dedicated to the student and take on a supportive role, and effective communication is key.¹¹¹ To accomplish this, the community organization should have a clear understanding of what it wants to gain from partnering with universities and students, ensure that they see their role as an additional resource and guide to students, and be as informed as possible about the university research and education processes.^{99,101,109,110,111} They should also have ongoing

⁸⁸ Nadimpalli et al., 2016

⁹⁹ Stoecker, 2008

¹⁰¹ Willis et al., 2003

¹⁰⁶ Stocking & Cutforth, 2006

¹⁰⁹ Stack-Cutler & Dorow, 2012

¹¹⁰ Sandy & Holland, 2006

¹¹¹ McIlrath, Maher & Mulligan, 2014

conversations with university partners/students, understand the responsibilities associated with partnering with universities and students, and play an active role in minding the partnerships.^{90,101,109,111} Finally, community organizations need to ensure that students feel they have the support of other members, feel their contributions are valued, and are treated equally during all phases of the project; have a contact person that has the capacity for the role in terms of time, passion and personality; and care should be taken to make sure that the project is beneficial to all parties.^{97,101,109,111}

Everyone involved should be knowledgeable about and responsible for meeting expectations for student research placements in community organizations, and frameworks designed to educate and support each and every stakeholder are necessary in order for a PAR effort to positively impact the community members and the junior researcher. Although gaining popularity and credibility, PAR is not yet part of the mainstream,⁶¹ and neither are the supports and resources for students who are motivated to undertake PAR for a thesis. While all social research projects are complicated, working in collaboration with communities creates challenges on top of those experienced by non-participatory researchers.^{61,93} And, of course, my suggestions are following from my own

⁶¹ Southby, 2017

⁹³ Klocker, 2012

⁹⁷ Puma et al., 2009

⁹⁰ Schwartz, 2010

¹⁰¹ Willis et al., 2003

¹⁰⁹ Stack-Cutler & Dorow, 2012

¹¹¹ McIlrath, Maher & Mulligan, 2014

experience. Other students may have had other experiences -more positive, or different types of challenges and complexities. Also, different agencies might have different ways of understanding and working with students. In any case, having the appropriate systems and supports in place can ease the burden on beginner researchers. This way, we students can pursue our goals of learning, having a greater sense of purpose in our research projects and participate in social, policy and organizational change; and communities can participate in studies that seek answers to questions they themselves see as important.¹⁰⁰ To help in this pursuit, sharing my experience and ideas might help the two cultures of graduate students and community groups in linking and adapting their research processes and needs to PAR. My university's school of social work education and school of graduate studies would be prime targets for the information I have acquired and I could present my insights and takeaways to them or participate in a workshop or field forum as a way to start disseminating what I have learned.

An action research project has the potential to be a highly rewarding experience for both the graduate student and the community partner,¹⁰⁰ and we need to embrace alternative ways of knowing and thinking about problems that moves us closer to where social justice is the norm.⁸⁹ I hope this thesis helps to bring us one step closer to managing the many ethical, logistical and practical concerns that are bound to come up in the messy process of research with a social

⁸⁹ Moore, 2004a

¹⁰⁰ van der Meulen, 2011

change agenda.

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