Job Retention and Career Development for People with Serious Mental Illness:

A Participatory Capacity Building Project

by

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A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Science

In

Rehabilitation Sciences

Faculty of Rehabilitation Medicine

University of Alberta

Abstract

Introduction: People with serious mental illness (PSMI) are capable and willing to contribute meaningfully to the workforce. However, a vast majority experience employment marginalization and hazardous work environments due to the stigma that portrays them as incapable or dangerous. Current support measures for PSMI in employment lack ongoing support, hindering their ability to address work-related challenges effectively. In contrast, PSMI have described peer support as an excellent source of time-unlimited support, as it operates on a reciprocal basis and is helpful for both acquiring and maintaining employment. Our research employs participatory action research (PAR) to harness its transformative benefits for PSMI. The benefits include fostering a collective consciousness among participants regarding the problem and a collective effort to discover relevant solutions.

Objectives: This participatory action research (PAR) project aimed at empowering PSMI to co-develop a peer-support network focused on building their repertoire as valued employees and identifying and managing challenges in achieving longer tenure and career advancement.

Methods: Ten PSMI as the co-researchers met weekly for ten consecutive weeks. Using a PAR approach, they collaboratively engaged in the steps in the action research cycle, including problem identification, planning, taking action, and evaluation of the action. Having identified the stigma of mental illness as the main problem influencing their job acquisition and maintenance, they collaboratively developed an educational resource as their first action step to reduce mental health stigma. There were two other action steps: collaboration with two like-minded organizations and the construction of a peer-led website that would serve as a hub of employment resources for peers and employers. The data gathered included recorded PAR sessions, group-developed materials, and the researcher's reflective notes. We utilized thematic analysis and generated our preliminary findings, which

were then confirmed through member checking to ensure they accurately reflected the collective experience of our co-researchers.

Findings: The findings of our research were described in two parts. Firstly, we described how engaging in PAR impacted our co-researchers. The group experienced transformative benefits of the PAR process, culminating in a peer support network, as we collaboratively engaged in three steps of the action research cycle. The development of a sustained partnership with our co-researchers is a novel contribution to the field, and our success in this area is due to the time we invested in establishing relationships, facilitating genuine power-sharing, and promoting peer support. Secondly, we described the factors that influenced our co-researchers' experiences at work. We used the Person-Environment-Occupation model as a framework to guide our understanding of the dynamic intersections among environmental, work-related, and personal factors that influenced our co-researchers' experiences of job acquisition and maintenance.

Conclusion: Through this research, we demonstrated the power of PSMI and their efforts to advocate their concerns of career advancement. Our focus on building a sustainable partnership with our co-researchers and our findings regarding a framework to conceptualize factors that influence job retention in PSMI were novel contributions to the field. These findings point to a poignant need to combat the stigma of mental illness and promote inclusive workplaces for PSMI. Additionally, we drew attention to the power imbalance inherent in the workplace that creates opportunities for employers to leverage their power to create psychologically safe work environments. This work not only shed light on the complexities surrounding job retention for PSMI but also offered a blueprint for peer support as an intervention.

Keywords: Peer support, employment, inclusive work environment, patient-led research, empowerment, stigma

Preface

This thesis is an original work by Elizabethmary Thomas. The research project entitled "Job Retention and Career Development for People with serious mental illness: A Participatory Capacity Building Project," of which this thesis is a part, received ethics approval from the University of Alberta Research Ethics Board (#Pro00123682, September 09, 2023). This project was funded by the Social Sciences and Humanities Research Council (SSHRC), Insight Development Grant (Grant # 430-2020-00983). A part of the literature review of this thesis was submitted for publication, cited as:

Thomas, E., Benjamin-Thomas, T., Sithambaram, A., Shankar, J., & Chen, S-P. (in press). Participatory Action Research Among People with Serious Mental Illness: A Scoping Review. *Qualitative Health Research*. I contributed to the research design and was responsible for data collection, analysis, and manuscript composition of this article. Sithambaram, A. assisted with data collection; Benjamin-Thomas, T., and Shankar, J. contributed to the manuscript edits; Chen, S-P was the supervisory author involved with concept formation, manuscript composition, and edits.

Acknowledgments

I want to express my sincere gratitude to my supervisor, Dr. Shu-Ping Chen, for her guidance, kindness, and patience in every step of my thesis. Thank you for the opportunity to work on this innovative research project that introduced me to Participatory Action Research. Your passion for occupational therapy, mental health care, and qualitative research is inspiring. I am also grateful to Dr. Janki Shankar for her valuable advice and suggestions throughout this thesis study. I would also like to thank members of my research lab for their encouragement and thoughtful suggestions.

I want to thank the members of HEAR US, without whom this research would not have been possible. Thank you for your vibrance, enthusiasm, vulnerability, and the overwhelming support you show for each other and our shared passion for creating inclusive workplaces and reducing the stigma of mental illness through increasing education and awareness. Thank you, Mr. Scott Davies (Supervisor at Cataloguing and Processing Services), for creating a supportive work environment that enriched my understanding of its value.

Finally, I would like to extend my heartfelt thanks to my friends and family, whose unconditional love and support got me through the transition to being an international student and the ups and downs involved in a master's thesis program. Thank you, Papa and Mummy, for motivating me to give my best in all I do. Steve, Samy, Joshua, and David, thank you for believing in me. I am grateful to my maternal grandmom, Mary, who made my master's studies possible, and to Refineria for the thorough proofreading. To my dearest husband, Jerin, my love, thank you for your thoughtfulness and encouragement through each step in the research and thesis write-up. I am grateful to God for the grace, wisdom, and endurance that he granted me throughout the research process.

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Chapter 1: Introduction

Work is crucial for the mental well-being and recovery of people with lived experience of serious mental illness (PSMI). Eklund and Leufstadius (2007) found that the duration and the personal significance of work engagements can alleviate symptoms and increase capabilities for PSMI. However, they encounter challenges in maintaining stable employment and advancing their careers, resulting in low job satisfaction and short job tenure (Negrini et al., 2014). To address these issues, this thesis presents a participatory action research (PAR) project engaging ten PSMI to identify challenges and develop grassroots-level solutions for job acquisition and maintenance.

In this introductory chapter, we adopt a Social Role Valorization (SRV) lens to understand the marginalization experienced by PSMI as a social construct rather than solely a medical or individual issue. We explore barriers to employment and existing support measures for PSMI in job acquisition and tenure. Additionally, we highlight the effectiveness of peer support as an ongoing solution for PSMI in their career journey. We also discuss the advantages of employing a participatory action research (PAR) approach to empower PSMI to form a peer-support group and facilitate collaborative solutions to the challenges they encounter in finding and retaining employment.

1.1 Understanding Barriers to Employment for PSMI Using the Social Role Valorization Lens

Research indicates that many PSMI strongly desire to work and possess valuable skills (Westcott et al., 2015). However, a significant majority (80%) of them are unemployed (Statistics Canada, 2018), and those who are employed often face short job tenure compared to the general population (Sauvé et al., 2021). These challenges in gaining and maintaining employment can be attributed to individual factors, such as treatment side effects and

cognitive difficulties, as well as broader socio-political factors, such as social stigma, lack of work accommodations, and limited opportunities due to neoliberalism in the job sector (Gühne et al., 2021; Gruhl, K.L.R, 2020; Rebeiro Gruhl, 2010). The Social Role Valorization (SRV) theory, developed by Wolf Wolfensberger (2011), emphasizes that the challenges faced by PSMI are often socially constructed.

SRV theory explains that social roles define how people perceive and value others in social interactions. Individuals are confirmed or devalued based on how well they fulfill their role expectations. Valued roles offer access to positive relationships, social networks, and material goods, leading to acceptance and respect by society (Wolfensberger, 2011). In contrast, being cast into devalued roles can lead to deprivation of opportunities and exclusion from social events, resulting in limited access to education, housing, and employment opportunities. PSMI often face challenges in building social networks, finding employment, and participating in community activities due to being cast into devalued roles (Wolfensberger, 2011).

These socio-political barriers perpetuate a cycle of occupational injustice, restricting PSMI from participating in activities and social environments that promote well-being and social inclusion. Prolonged unemployment exacerbates the situation, leading to dependency, financial insecurity, and increased stigmatization of PSMI. Addressing these challenges has prompted the development of programs and measures to support PSMI in overcoming barriers to employment (Laliberte Rudman & Aldrich, 2016).

1.2 Measures to Support Employment for PSMI

Various measures have been implemented to support PSMI in overcoming employment barriers, such as social enterprises and supported employment (SE) programs like Individual Placement and Support (IPS). Social firms, also known as social enterprises, facilitate social and work integration by providing productive activities, tailored support, and

training for relevant qualifications (Villotti et al., 2017; Williams et al., 2010). IPS helps PSMI secure competitive jobs quickly and provides continuous clinical support (Drake et al., 2012). More recent approaches include augmented supported employment programs (SE+) that incorporate cognitive remediation therapy (McGurk et al., 2016) and cognitive behavior therapy (Lecomte et al., 2020). However, standalone therapies may not be well-suited to the occupational context, as they potentially hinder the transfer of acquired skills and knowledge to the workplace and reduce motivation to complete the program (Chan et al., 2015; Keefe et al., 2016). Studies suggest that continuous ongoing support tailored to individual needs is effective in supported employment programs (Morrow et al., 2009; Corbiere et al., 2017). However, program implementation and funding limitations may hinder service providers' ability to provide such support (Mental Health Commission of Canada, 2015). Peer support, which is gaining popularity as an effective solution for the ongoing support needs of PSMI, can address this challenge.

1.3 The Value of Peer Support in Facilitating Employment for PSMI

A successful career pathway for PSMI involves recognizing valuable community resources. For instance, social integration and networking, including connections with family and friends, positively impact self-care and employment outcomes (Bromley et al., 2013). In particular, peer partnerships with individuals with similar challenges foster hope, recovery, and empowerment (Rebeiro Gruhl et al., 2016). Peer support, a crucial recovery-oriented approach, is linked to positive changes in various aspects of PSMI's lives, such as physical activity, self-efficacy, depression reduction, and perceived social support (Lloyd-Evans et al., 2014; Repper & Carter, 2011; Davidson & Guy, 2012).

Vocational-focused peer support groups enhance readiness for work-related goals, vocational hope, and quality of life for PSMI (Kern et al., 2013; Chien et al., 2019).

Collaborative partnerships, both on and off work, help PSMI develop self-management strategies, transition from service users to providers, and embrace mainstream employment. Positive group discussions on employment help boost motivation and build persistence in overcoming work-related challenges (Bell, 2012; Killeen & O'Day, 2004). By learning from and supporting each other, group members improve goal-setting and problem-solving skills, enhancing stress management at work. A safe peer environment facilitates effective problem-solving, receiving criticism, and benefiting from feedback (Chien et al., 2019). However, limited research on the specific benefits of peer support in PSMI's work outcomes and experiences emphasizes the need for further exploration into whether peer support can effectively provide the time-unlimited support required by PSMI. To address this gap, we engaged PSMI in the research process using participatory methods to gain valuable insights into the effectiveness of peer support for their unique needs.

1.4 The Value of Engaging a Participatory Action Research Approach to Empower PSMI

Participatory and community-based approaches have brought sustainable changes in societal attitudes toward PSMI (Cabassa et al., 2013; Lapadat et al., 2020). Participatory action research (PAR) is an effective way to enhance the relevance of scientific research, bridge the gap between science and service, and promote evidence-based practice in healthcare (Herr & Anderson, 2015). Collaborating with PSMI increases the likelihood of asking relevant and usable questions, believing and acting on results, and empowering them through the research process. A recent scoping review of PAR in PSMI revealed the empowering benefits of this research approach as it builds capacity, increases their sense of agency to guide decisions concerning them, and facilitates the establishment of sustained social networks (Thomas et al., 2023). Empowerment themes are especially crucial in research with PSMI as they have been historically marginalized, and their perspectives are

not adequately highlighted. The necessity to increase the capacity of PSMI to access their right to job tenure and career advancement led to the development of our participatory action research project.

1.5 Outline of this Study

1.5.1 The Context of this Study

This study represented the second phase of a larger capacity-building project aimed at assisting PSMI in maintaining employment and advancing in their careers. The first phase aimed to understand the key ingredients contributing to job retention and career progression among PSMI. To achieve this, we conducted a literature review and semi-structured interviews with three key stakeholder groups: PSMI, experts from employment service programs for PSMI, and employers who have hired PSMI. The themes that emerged from both our literature review and the thematic analysis of the interviews shed light on PSMIs' perceived need for continuous, ongoing support to achieve longer job tenure. Additionally, Phase One findings also highlighted the value of peer support as a consistent and unlimited resource. We used these findings to develop a preliminary framework for job tenure and career advancement. This framework then informed our discussions with PSMI in the initial part of the PAR project.

In this thesis, we discuss the second phase of our project. Using a PAR approach, we collaborated with 10 PSMI who were employed and interested in research related to sustained job tenure and career advancement. PAR requires that the research participants, whom we refer to as co-researchers, drive the objectives of the research process. Our research team shared the findings from phase one with our co-researchers, who concurred about the benefits of peer support in retaining their jobs. Over ten consecutive weeks, our co-researchers collectively identified challenges to achieving job tenure. They also brainstormed and

implemented relevant solutions. This thesis outlines how the PAR process empowered our co-researchers, ultimately leading to the development of a sustainable support network that enhances their skills and addresses barriers potentially hindering job tenure and career advancement for PSMI.

1.5.2 Research Question

From our findings in the first phase of this study, we developed preliminary research questions to guide our preparation for engaging in PAR research. Our initial research question was, "How can we empower PSMI to sustain their jobs?" Adhering to PAR principles, we allowed our co-researchers to direct our objectives throughout the research process. Thus, we approached this preliminary research question flexibly, remaining open to modifications based on our co-researchers' suggestions. As the research progressed, in collaboration with our co-researchers, we reframed the research question to "How can we sustain our jobs?" This shift reflected our co-researchers' ownership of the research process.

1.6 Definitions of Key Terms

People with Serious Mental Illness (PSMI): Although the term "serious mental illnesses" (SMI) encompasses a variety of diagnoses, for this study, the term "People with Serious Mental Illness" (PSMI) is used to describe individuals with a diagnosis of schizophrenia, bipolar disorder, and any form of a psychotic disorder (National Collaborating Centre for Mental Health, 2014). In our research, we use the term PSMI to mean *people with lived experience of serious mental illness,* as our co-researchers suggested this term to be more strength-based than people with serious mental illness.

Supported Employment (SE): The American Psychological Association defines supported employment as a vocational rehabilitation program that places individuals with disabilities directly into the paid competitive working environment as quickly as possible. An emphasis

on matching an individual with an appropriate employer and work environment involves

individualized, rapid placement and ongoing support, training, and assessment considering

the person's vocational and personal needs (American Psychological Association, n.d.)

Peer support: The Center for Addiction and Mental Health defines peer support as a process

through which a person or group with a specific experience or health condition provides

emotional, social, and informational support to individuals with similar experiences or

conditions (Center for Addiction and Mental Health, 2018).

1.7 Thesis Outline

This thesis is constructed using a traditional thesis format divided into five chapters.

Chapter 1, *Introduction*, includes background and context, the study objectives, definitions of

key terms, and the conceptual framework used to inform the research. Chapter 2, *Literature*

Review, reviews the available literature on job tenure and career advancement in PSMI.

Chapter 3, *Methods*, contains the study design, describing PAR and the action research cycle,

the data generation process, the data analysis method, and detailed explanations of the steps

in the action research cycle. Chapter 4, *Findings*, presents the findings and the information

generated through this study. Chapter 5, *Discussion and Conclusion*, summarizes the overall

findings, the limitations of this thesis, and the implications for future research.

Chapter 2: Literature Review

In order to better understand employment in PSMI, we thoroughly reviewed the literature on the importance of employment in improving the well-being of individuals with lived experiences of mental illness. The first part of the literature review describes how employment influences a person's well-being. We review the benefits employment brings to PSMI, their current job scenario, the hurdles they face during a job hunt, and the factors that affect their job tenure. We then explore programs that support PSMI in their career journey. The benefits of these programs and the need for continuous ongoing support that persists despite the available supportive measures are reviewed. Finally, the role of peer support as a possible way of enabling and sustaining work participation is reviewed.

The second part of the literature review describes social role valorization theory as a lens that frames our understanding of the social determinants of the challenges faced by PSMI and possible ways to help them develop valued roles that would facilitate gaining and maintaining employment. In the third part of this chapter, we review the use of Participatory Action Research (PAR) as the research methodology for this study. We discuss techniques found in the literature to empower PSMI and to help them cope with challenges faced during the research process.

2.1 Employment and PSMI

Research shows that employment and supportive relationships are strong predictors of well-being. Engaging in paid employment has predicted individual satisfaction and a sense of accomplishment (Myers, 2003; Warr, 2003). The apparent benefit of paid employment is an increased income, leading to increased access to resources and services. In their book about productivity and happiness at work, Robertson and Cooper (2011) illustrate that work has

many benefits beyond economic reward. It provides structure and purpose to people's everyday life. This sense of direction is a crucial facet of psychological well-being. Work can also provide opportunities for personal growth and positive relationships with others (Ryff, 2014). In turn, well-being results in better work engagement and enhanced job satisfaction. On the other hand, unemployment can hurt both long-term and short-term well-being (Warr, 2003).

2.1.1   *Benefits of Employment in PSMI*

Unemployment often has a more significant impact on communities marginalized due to disabilities. A recent study by Statistics Canada shows that 36 % of people with a chronic disability reported being unemployed (Statistics Canada, 2020). People with serious mental illness (PSMI), in particular, face many challenges in finding and keeping employment. Studies show that up to 80% of PSMI are unemployed despite a strong desire to work (Carmona et al., 2017; Evensen et al., 2016). They also face lifelong disruption in work participation and economic marginalization (Salkeveret al., 2007; Waghorn et al., 2012; Westcott et al., 2015). Furthermore, among PSMI who are employed, the average duration of employment is eight months, in contrast to 9 years in the general population (Sauvé et al., 2021). Low involvement and attachments to the labor market have resulted in this population not being able to fully experience the economic and social benefits of work participation.

1. **Social Integration.** Research shows that getting and holding a job improves perceived health and well-being in PSMI. It improves their self-rated scores regarding their quality of life, feelings of mastery, satisfaction with daily occupations, and psychosocial functioning (Eklund et al., 2004). While being an employee is a valued role for this community, research shows that they also perceive being a trainee or being engaged in education as a highly valued occupation (Evans & Repper, 2000;

Haertl & Minato, 2006). Other significant benefits of being employed include having a social identity as an employee and a workmate and a feeling of acceptance and belonging. In a study about the personal meaning of working, participants reported that being employed helped them feel like they belonged to their society. This feeling strengthened their self-esteem and conferred a degree of status whereby they were treated with more excellent value in society. Work was also described as an avenue for developing new social connections and relationships with their colleagues that were a source of support. This social support was reported as a necessary factor in helping them continue working (Hammel, 2004; Leufstadius et al., 2009)

2. **Improved Work-Related Skills.** Engaging in employment helped PSMI develop valuable executive skills, including an improved ability to plan and organize tasks and problem-solve when facing work challenges. The opportunity to engage in tasks regularly facilitated enhanced self-confidence. Notably, they perceived work as less meaningful if tasks were too complex or easy. It was essential to meet the "just right" level of challenge, where the work tasks and environmental demands were sufficiently challenging and required some thought and creativity, while also giving PSMI a feeling that they have the resources and skills necessary to cope with the tasks (Honey, 2004; Woodside et al., 2006).

3. **Occupational Balance.** Work was found to provide structure and stimulate creativity in the everyday lives of PSMI. This helped them be active and was perceived as a source of energy and pleasure, as it helped them realize that they could take up and fulfill workplace responsibilities. It also improved their occupational balance, as they had a daily rhythm, including definite periods of work and leisure (Gahnström-Strandqvist et al., 2003; Krish, 2000; Leufstadius et al., 2006).

4. **Increased Access to Resources and Financial Security.** Improved financial security as a result of work helped elevate the quality of life of PSMI and their families. This led to increased access to material resources, including nutrition and clothing, improved participation in social activities of their choice, and enhanced quality of life. (Razzano et al., 2005). Increased financial resources and paid vacations translated into increased access to and participation in other occupations of interest. Engaging in work had a spin-off effect and energized them to become more occupied at other times (Leufstadius et al., 2009).

2.1.2   *Job Acquisition*

PSMI face significant challenges in seeking jobs and securing employment. Many personal and socio-political factors influence job acquisition in this vulnerable population. Some of these factors are elaborated below.

1. **Personal Challenges.** Personal factors play a crucial role in job acquisition for individuals with mental illness. These factors include resources to manage symptoms and cope with job searching, educational background, previous employment experiences, age, familial and cultural values, and the influence of kinship networks (Fossey & Harvey, 2010). Young adults with mental illness may face challenges as they learn to manage symptoms while balancing daily routines (Torres Stone et al., 2018). Inadequate educational credentials and limited work experience during schooling can further hinder their job prospects and transition to adulthood (Torres Stone et al., 2018). Prior employment history strongly predicts vocational outcomes, but episodic ill health patterns can disrupt workforce participation (Honey, 2003; Waghorn et al., 2002). Additionally, individuals with mental illness encounter various personal challenges, including physical, cognitive, and emotional difficulties

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stemming from medication side effects and the nature of their illness (Carra et al., 2019).

2. **Socio-Political Challenges.** More prominent socio-political factors that influence job acquisition include the presence of neoliberalism in the hiring process in the job market, the presence of stigma and discriminatory hiring practices, and a prevalent discourse that casts PSMI as incapable, incompetent, and dangerous. This is coupled with challenges in accessing education and training resources, which leads to PSMI being placed in entry-level, often precarious jobs. Furthermore, government services and policies meant to support these individuals in getting jobs may have rigid rules and funding patterns and often fall short of their main goal because they are not tailored to meet their job-related needs (Gruhl, 2020; Rebeiro Gruhl, 2010, 2012).

2.1.3   Job Tenure

For PSMI who can find a job, maintaining their job remains a significant challenge. The average tenure in paid employment for PSMI varies between 18 and 30 weeks across studies internationally (Bond et al., 2008; Bond & Kukla, 2011a; Heffernan & Pilkington, 2011). Many contextual factors and personal challenges cause people with lived experience of mental illness to lose or leave their current job. Contextual factors that influence job tenure may broadly be classified as difficulties regarding the nature of the work, the workplace environment, and the workplace culture and availability of support. Employment circumstances, including adequate pay and benefits and whether the job was ongoing or temporary, influenced tenure (Kukla & Bond, 2012). More prominent environmental factors like inefficient infrastructure and public transport options limited their ability to work (Huff et al., 2008). In summary, PSMI may find work more physically and psychologically demanding, especially during the initial stages of employment or returning to work. A conflict between work and their health may make it challenging to use their internal and

external resources to retain the job. This means that it is particularly important to focus on developing personal resources and external supports such as social support networks, including family, friends, health care providers, and peers, to help them maintain wellness at work and thereby support job tenure (Glover & Frounfelker, 2013; Roberts et al., 2010).

In a recent literature review aimed at understanding factors contributing to job tenure across 19 studies, Williams and colleagues (2016) reported three main factors: the worker's experience of doing the current job, natural supports in the workplace, and strategies for integrating working recovery and wellness.

1. **The Experience of Doing the Current Job.** Studies showed that participants who rated their job as satisfying were content with the type of work. They perceived the variety of tasks offered as interesting and enjoyable during the first three to six months and achieved longer tenure (Kukla & Bond, 2012; Williams et al., 2012). PSMI report that their motivation to continue working was better supported in jobs that reinforced their sense of personal competence and when they could identify work experiences that gave them confidence (Auerbach & Richardson, 2005). This sense of competence was further bolstered when they had opportunities for educational training, which helped them advance in their careers (Killeen & O'Day, 2004; Williams et al., 2012). Additionally, a good understanding of the benefits system enabled PSMI to balance work and income benefits, which also helped them to maintain their job (Salyers et al., 2004).

2. **Natural Supports in the Workplace.** Workplace support that reinforces job tenure includes the quality of workplace interactions, relationships, and work culture. The supervisor's perceived qualities and interactions with them, particularly, were found to influence tenure (Franke et al., 2014; Resnick & Bond, 2001). Additionally, co-workers who were reassuring, supportive, approving, inclusive, and friendly helped

PSMI maintain their jobs. Notably, encouragement and positive feedback offered by the customers they serve while working were also reported by PSMI as significant in facilitating job tenure. A respectful, communicative, and accepting workplace culture that supported disclosure and demonstrated concern for the workers' welfare facilitated increased job attachment and positively influenced tenure (Kirsh, 2000; Pischel & Felfe, 2023; Secker & Membrey, 2003).

3. **Strategies for Integrating Employment with Recovery and Wellness.** PSMI work around the symptoms of their illness and the side effects of medication to integrate employment along with their recovery journey. They often draw upon both internal and external resources in order to meet the challenges of everyday life. Job security and access to benefits, like additional unpaid sick leave and superannuation, were perceived as supportive of job tenure (Williams et al., 2012). The review found that workers who achieved longer job tenure perceived work as facilitating recovery by helping them shift their focus away from their illness (Kirsh, 2000; O'Day et al., 2006). They relied on internal resources like identifying personal strategies to manage their symptoms while working and engaging in various coping and problem-solving strategies that enabled them to maintain their career during their recovery journey (Auerbach & Richardson, 2005; Becker et al., 2007).

    Noteworthy external resources that positively influenced PSMI and their ability to maintain work and wellness include their social support networks comprising family, friends, peers experiencing mental illness, mental health care providers, and employment specialists. They valued consistency and trustworthiness as helpful traits in their support networks. They also valued people who acknowledged their capabilities and encouraged resilience, were available as well as collaborative in the ways that they helped PSMI deal with challenges to mitigate

work-related struggles (Auerbach & Richardson, 2005; Becker et al., 2007; Killeen & O'Day, 2004). When it came to employment specialists, supportive actions like helping PSMI negotiate accommodations and work conditions, in-person contact during sessions (Bond & Kukla, 2011b), being flexible, and giving just the right amount of support was reported as helpful (Killeen & O'Day, 2004; O'Day et al., 2006). Personal resources and external support networks also impacted employment and wellness (Auerbach & Richardson, 2005; Becker et al., 2007).

2.1.4 *Programs to Support Employment in PSMI*

The last few decades have seen an increased awareness regarding the capability of PSMI to acquire jobs and progress in their career, as well as the need for resources and policies to support them in their endeavor. Accumulated evidence over the last twenty years shows that Supported Employment (SE), based on Individual Placement and Support (IPS), has gained recognition as a clearly defined, evidence-based vocational intervention for PSMI (Bond et al.,2008; Kinoshita et al., 2013; Waghorn et al., 2014). Many studies report that this approach achieves better employment outcomes than prevocational training and sheltered workshops (Suijkerbuijk et al., 2017). Despite these findings, it was observed that roughly half of IPS participants do not achieve job placement, and for those who do, their tenure often lasted less than six months (Gewurtz et al., 2012; Williams et al., 2016). Researchers have tried augmenting IPS with adjunct interventions to address these challenges, including social skills training, cognitive remediation, psychological interventions, cognitive behavioral interventions, and motivational interviewing. Supported education is another method to increase skills and job satisfaction that would likely enhance job tenure (McDowell et al., 2021).

Another service designed to help PSMI enter the workforce is known as Social Firms or Social Enterprises. They have features that effectively promote work integration and job tenure for PSMI, including high levels of social support at the workplace, availability of numerous work accommodations, and a non-discriminatory work environment (Villotti et al., 2018). Social firms provide remunerative work for PSMI while at the same time promoting their physical, social, and mental health. These enterprises facilitate social and work integration through engagement with productive activities, tailored support, and training to develop relevant qualifications. Various employment opportunities are made available for PSMI through social firms. These include work in cleaning, catering, and jobs in industries. Social Enterprise has proven to be an effective model for enhancing skills, employability, and self-confidence and developing their identity as productive workers (Villotti et al., 2018; Williams et al., 2010).

While great strides focus on supporting employment in PSMI through IPS, adjunct therapies, and social firms, they continue to express their need for consistent and ongoing support on and off work. Although time-unlimited support is one of the critical principles in IPS, the realities of resource constraints result in a dilution of these goals (Mental Health Commission of Canada, 2015). The challenges in integrating with their role at work, which could be resolved in collaboration with a support network, are often exacerbated due to lack of support. Studies have shown the value of family and peer support networks in coping with the often-fluctuating symptoms and maintaining employment in PSMI (Lopes, 2005). Peer workers' support effectively fulfills the need for ongoing support, as peers draw upon their own lived experiences and often have an insider's perspective regarding what is considered helpful in mitigating ongoing challenges (Rebeiro Gruhl et al., 2016).

2.1.5   Peer Support

The existing literature regarding peer support shows the positive impact that this service has on PSMI in the domains of social support, community integration, personal empowerment, quality of life, reducing distress regarding persisting symptoms, adherence to treatment, and participation in health care and rehabilitative services (Doughty & Tse, 2011; O'Hagan et al., 2010; Gruhl et al., 2016). Bellamy (2017) and colleagues, in their report on the growing evidence base for peer support services, observe that it positively impacts levels of hope, empowerment, and quality of life in PSMI. The peer-based health interventions in their review included smoking cessation, self-management, and healthy lifestyle development. The health outcomes also covered a range of areas, including self-management attitudes and behaviors as PSMI began to set goals and problem-solve, health behaviors including managing their diet, physical activity, and improved medication adherence. Other health outcomes include self-rated health status and self-reports of symptoms or health complaints, quality of life, and health care services (Bellamy et al., 2017).

Within a work context, peer support programs have recently been recognized as facilitating mutual support among employees and decreasing perceived workplace stress. Mead and colleagues (2001) have defined peer support as "a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what was helpful" (p. 6). A key characteristic of peer support is social reciprocity between individuals who share similar life experiences and better understand a peer's situation. Peer support fosters resilience and has the potential to prevent behaviors like absenteeism, disengagement, and intentions to leave the organization (Whybrow et al., 2015). It can also facilitate more positive attitudes toward work and personal well-being, with increased positive coping strategies like exercise and decreased negative coping strategies like using

alcohol to cope with distress (Williams-Piehota et al., 2008). Studies also found that peer support can help decrease presenteeism and lower the rate of sick leaves (Odeen et al., 2013).

Many PSMI describe challenges in maintaining a work-life balance due to the hectic nature of their schedules and meeting deadlines in competitive work environments. In these scenarios, peer support was found to protect working PSMI from various stressors by helping them develop resilience, which enhanced their well-being and improved their mental health (Grant et al., 2009; Vanhove et al., 2016). The common background and experiences of peers lead to empathy, credibility, modeling of positive coping behaviors, fostering a sense of trust, and helping them establish shared frameworks for communication and partnership with similar peers (Vaughn et al., 2018).

2.2 Social Role Valorization Theory as it Relates to Employment in PSMI

In the second section of this literature review, we explore the Social Role Valorization Theory (SRV) (Wolfensberger, 2011) as a guiding framework to analyze the social determinants impacting the work-related challenges faced by PSMI. This perspective guides our investigation into potential strategies that can aid them in developing valued roles, thus improving their prospects for gaining and maintaining employment. Wolf Wolfensberger observed that people relate to each other primarily based on their social roles. He defined social roles as "a combination of behaviors, privileges, duties, and responsibilities that are socially defined, is widely understood and recognized within a society, and is characteristic or expected of a person occupying a particular position within a social system" (Flynn & Lemay, 1999; p.126) These roles serve as the medium through which people relate to others, and decide whether to value someone positively. Wolfensberger described social devaluation as a phenomenon where perceivers attribute a low or negative value to an individual or group. This implies that some people may be considered less valuable than the perceiver, which can

happen at individual or community levels. Negative evaluations are often on an unconscious level compared to positive ones. Wolfensberger coined the term social role valorization (SRV) and defined it as "The application of what science has to tell us about the enablement, establishment, enhancement, maintenance, and defense of valued social roles for people." (Flynn & Lemay, 1999; p.125). The SRV theory recommends crafting enhanced social roles for individuals who have been systematically devalued, using the existing knowledge and experience (Lemay, 1995; Wolfensberger, 2011).

Social devaluation can impact employment, particularly for marginalized people at risk of being seen negatively by society. PSMI are often cast into a devalued role due to the prevalence of a dominant discourse about them being unemployable or dangerous (Rebeiro Gruhl et al., 2012). It is essential to consider how they are treated in employment contexts and identify their workplace roles. In many instances, while fulfilling the role of an employee, an individual with lived experience of mental illness may be seen predominantly as a client of a supported employment program who is allowed to work and who may be fulfilling the employer's altruism to help the less fortunate, as opposed to being seen and treated as a contributing member of the workforce (McVilly, 1992). The SRV theory explains how promoting understanding about what it means to hold a valued social role as an employee among employers, colleagues, and working PSMI would mutually benefit everyone in the workforce (Aubry et al., 2013).

In order to craft enhanced social roles for PSMI, formal SRV theory describes a three-stage feedback loop for how these roles are communicated, learned, and reinforced (Flynn & Lemay, 1999). The first stage includes conveying role expectations using five kinds of role communicators: the physical environment, the prevalent norms in their social context, language, personal presentation, and other miscellaneous factors specific to the individual's needs. This is followed by the second stage when the individual develops a positive social

role and confirms the role expectations. When the resulting changes in their behavior are noticed and reinforced by others, they further confirm these role expectations. Continuing this loop of confirming and reinforcing role expectations leads to the individual becoming strong in the positive role. SRV theorists recommend using participatory approaches to enhance participants' understanding of a valued social role and ways to develop it in their contexts (Tyree et al., 2011).

In this thesis study, we engage the SRV lens to understand the employment-related challenges faced by PSMI. This would empower our co-researchers to develop a positive social role expectation, gain a fresh perspective regarding their challenges, and empower them to help each other reinforce valued social roles in their work contexts. We expect that supporting each other in creating and maintaining these valued social roles would, in turn, bolster their self-esteem and positively influence their job tenure and career progression.

2.3 Review of the Methodology

In the third section of this literature review, we explore the application of Participatory Action Research (PAR) as the research approach for this study. Understanding how participatory research has been valuable, the challenges faced during PAR projects, and suggestions for practice from previous research would inform the current study in engaging PSMI in participatory research (Desai et al., 2019). As a part of this larger participatory capacity-building project, we completed a scoping review to map the nature and extent of participatory research with PSMI (Thomas et al., 2023). We have provided a summary of our review here. Please refer to Appendix I for the complete article.

Our review of previous Participatory Action Research (PAR) studies highlights the advantages of involving PSMI in the research process, providing them a platform to voice their concerns and empowering them. The scoping review aimed to summarize the use of participatory research in this marginalized community, examining areas of focus, methods,

and outcomes of PAR with PSMI while learning from challenges faced and recommendations for empowering people with lived experience of serious mental illness.

The scoping review included 87 PAR studies published from 1997 to 2021. Most of these studies were published in North America (74.7%) and recruited participants with serious mental illnesses of varying diagnoses. Based on PAR principles, most studies involved relevant stakeholders, including PSMI, throughout the research process. Studies in this review have prioritized three main research areas: activity and participation, including social integration, self-care, and employment (29%); environmental aspects, including stigma, supported housing, and mental health services (41%); and the overall recovery conception of PSMI (17%).

An essential goal of participatory research is to empower participants to become aware of and develop agency to advocate for their needs and those of their community. In the 87 reviewed studies, we found five critical strategies to empower participating PSMI: (1) building capacity, (2) balancing the distribution of power, (3) creating a collaborative environment, (4) peer support, and (5) enhancing engagement in the research process.

Various strategies have been employed to enhance PSMI's capacity in participatory research, such as training in research skills and developing tools to evaluate mental health services (Barrow et al., 2014). Creating a safe space is vital for improved participation, achieved by avoiding jargon, fostering inclusivity, and supporting PSMI as they learn (Maniam et al., 2016; Schneider et al., 2004). Additionally, offering incentives like gift cards, meals, and transportation reimbursement encourages continued participation. Flexibility in research sessions, including venue, time, duration, frequency, and location (e.g., Fernandes, 2012), and allowing expression of residual thoughts during project closure (Timmers et al., 2013), effectively engage participants.

Participatory Action Research (PAR) empowers individuals with lived experience of serious mental illness (PSMI) to drive changes in their lives through research. Our scoping review revealed several benefits of PAR, including prioritizing relevant issues and raising public awareness while reducing stigma (Sims-Gould et al., 2017). Although beneficial, PAR may pose challenges like anxiety, coping difficulties, and cognitive issues for PSMI. Procedural challenges, such as high attrition rates and conflicting priorities, can also emerge (Tischler et al., 2010). However, collaborating with co-researchers and innovative data collection methods can overcome these challenges, providing a platform for PSMI to freely express their concerns and overcome marginalization (Whitley et al., 2020).

2.4 Summary of the Literature Review

To sum up, the literature review focuses on the benefits of employment and the current work situation for people with serious mental illness (PSMI). We shed light on the obstacles they face while searching for and holding onto jobs (Becker et al., 2007) and use an SRV lens to understand the factors that affect job acquisition and retention, as well as the support programs available to assist PSMI in their career path (Aubry et al., 2013). Despite the existing support systems, there remains a need for continuous support both on and off work. Peer support may be a viable solution to address this gap in employment support services for PSMI (Repper & Carter, 2011). Moreover, participatory action research is an empowering approach that can be used to identify specific ways to enhance involvement and empower PSMI throughout our research process.

Chapter 3: Methods

We used Participatory Action Research (PAR) to build capacity and identify ways to sustain employment and career advancement for PSMI. PAR is a form of qualitative research where participants, as co-researchers, work together with researchers to set the priorities and direction of the study, with a focus on active engagement, and through that process, are empowered towards taking action and bring about social change (Danley & Ellison, 1999; Brydon-Miller et al., 2020). We received approval to begin this research project from the university research ethics office (Pro00123682). We have further described the unique features of this empowering approach below.

3.1 Overview of PAR

3.1.1 *What is Participatory Action Research?*

Participatory Action Research (PAR) is an empowering process that goes beyond traditional research methodologies, as it leads to the creation of new knowledge through collaboration and shared experiences (Fals-Borda & Rahman, 1991; Reason & Bradbury, 2005). Social researchers have come to recognize that theoretical knowledge, while valuable, may not always address real-life problems effectively (Jacobs, 2018). Therefore, PAR emphasizes generating solutions in partnership with community members, valuing experiential learning and the insights gained from living within social contexts and ordinary conversations (Fals-Borda & Rahman, 1991). This experiential knowledge has practical implications and can drive positive changes in practice (Baum et al., 2006).

What sets participatory research apart from other methodologies is its emphasis on equal partnership between researchers and community members, sharing experiences, and a commitment to positive social change by adapting practices to suit their needs (Wallerstein & Duran, 2008; Brydon-Miller et al., 2020). Traditionally, PAR has focused on marginalized

communities facing various challenges related to race, ethnicity, gender, disability, and poverty, such as rural populations, refugees, people with disabilities, and new immigrant communities (Hacker, 2013; Minkler & Chang, 2014). These communities often lack access to knowledge and have limited representation in decisions affecting them. Engaging in participatory research empowers individuals within these communities, enhances their capacity, and allows them to advocate for improvements in their lives.

Over the past three decades, PAR has significantly empowered marginalized populations, including People with Serious Mental Illness (PSMI) (Schneider, 2012). This approach has provided PSMI with a platform to voice their experiences, needs, and aspirations, ultimately leading to more effective interventions and support tailored to their unique circumstances. We have elaborated below how this approach aligned well with our project's goal of empowering participants by actively involving them in the research process.

3.1.2   Rationale for Using PAR in This Study

This research aims to empower PSMI to sustain their jobs using a PAR approach. This approach leverages the unique perspectives and lived experiences of PSMI, who possess an unparalleled understanding of their needs and valuable insights into how to address their concerns effectively. By actively involving PSMI in the research process, we aim to foster a sense of agency and empowerment within this marginalized community, enabling them to drive positive changes in their work contexts. PAR creates opportunities for PSMI to acquire transferable skills and form social connections while ensuring genuine power-sharing, mutual respect, and informed decision-making. The core values of PAR, which include mutual respect, genuine power-sharing, and maximizing the engagement of PSMI, align seamlessly with our research objectives of empowering this community to collaboratively create a support network that facilitates job tenure and career advancement. Therefore, adopting a PAR approach creates an environment where PSMI can contribute their unique perspectives,

develop essential skills, and work together towards sustainable job opportunities and career advancement. We elaborate on the PAR framework we used to guide our research below.

3.1.3. PAR Framework

We employed a five-step action-research cycle as a methodological framework for our research. Kurt Lewin originally described action research as a process involving planning, implementing the plan, observing outcomes, and revising the plan based on observations (Lewin, 1946). Building on this idea, Kemmis and colleagues (2014) presented these steps as a spiral, acknowledging that the reality of action research is often more flexible and dynamic. The steps may overlap, and initial plans can evolve based on new insights gained through experiences. Our adaptation of the action research cycle, as illustrated in Figure 1, follows the approach proposed by Kemmis et al. (2014, p. 29). The five steps in our action research cycle are as follows:

1. **Identifying the Problem.** The first step in the action research cycle is the planning phase, where the primary objective is to foster a collective understanding of the problem at hand. This problem could be a challenge, a deficiency, or an opportunity for improvement within a specific community or setting. Once the problem is clearly defined, this step involves collaboratively selecting a focused area of inquiry for the current action research cycle. The group collectively frames a research question to guide subsequent actions in this phase.

2. **Deciding and Implementing the Action.** After identifying the problem, the next step in the action research cycle is to create a comprehensive plan for addressing the issue. This plan involves several crucial aspects: setting clear goals, defining the project's scope, outlining the methods and strategies to be employed, establishing a timeline for implementation, and deciding on a way to measure the effectiveness of the action. Once the plan is formulated, the proposed interventions or changes are implemented.

This entails executing the strategies and activities outlined in the action plan. Throughout this phase, data is gathered to carefully monitor progress and measure the impact of the implemented action steps.

3. **Evaluating the Action.** During the action planning step, the group creates an outcome measure to evaluate the actions' effectiveness. Once the plan is implemented, the effectiveness of the outcomes and results are evaluated using the predefined measure. Throughout this step, observations are recorded, and the collected data are analyzed collaboratively within the specific context of the research.

4. **Data Analysis.** The research team collaborates with the co-researchers to jointly analyze the gathered data. Often, they use a conceptual lens derived from existing literature to gain deeper insights into the data trends. While the meanings of the data are considered throughout the action research cycle, it is crucial to withhold judgment until patterns in the data become evident (Kemmis & McTaggart, 2007). This approach ensures a thorough and unbiased examination of the data, leading to more meaningful and valid findings.

5. **Reflecting on the Outcomes of the Action Taken.** After conducting the evaluation and reflection, the research team and participants make informed decisions about the success of the implemented action steps. They collaboratively reflect on the outcomes and effectiveness of the actions, assessing whether the desired goals were achieved. Based on this assessment, they determine the feasibility of continuing with another action research cycle.
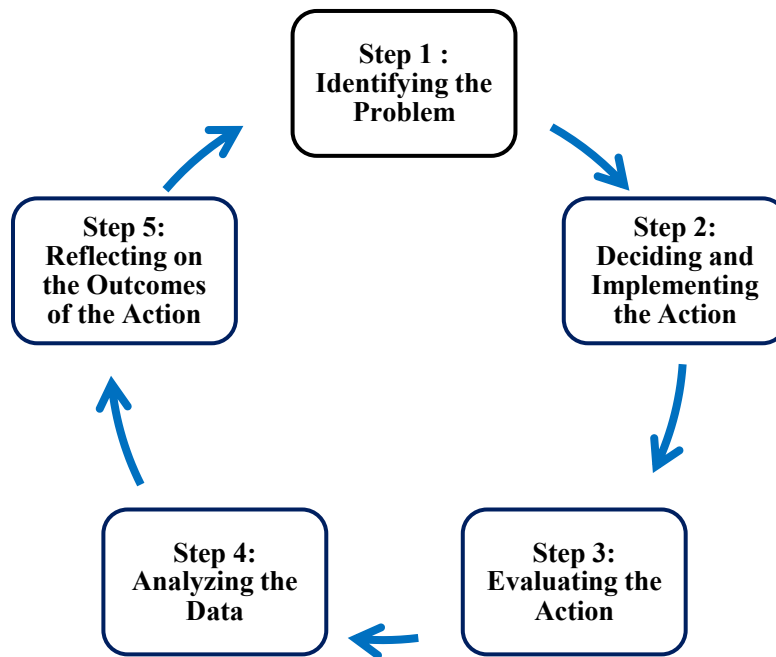
Figure 1. Action Research Cycle. (Adapted from Kemmis et al., 2014, p. 29)

3.2 Participant Recruitment

3.2.1 *Inclusion and Exclusion Criteria*

Our study included individuals who identified as having a serious mental illness (SMI), such as schizophrenia, bipolar disorder, and other psychotic illnesses. These participants were employed, could commute to the venue for the PAR sessions, and provided their consent to participate. Those who did not have psychotic illnesses, were not currently employed, or had co-morbidities that hindered their ability to participate were excluded from the study.

3.2.2 *Recruitment Process*

To begin recruitment, we shared e-posters and flyers with information about the study and inclusion criteria (see Appendix B) with a key contact at three participating sites: (1) the Supported Employment program of Addiction and Mental Health Services Edmonton, (2) Prosper Place Clubhouse (a community clubhouse program in Edmonton), and (3) On-Site Placement (a non-profit organization that helps PSMI with vocational training and job

placements). The key contacts shared details about the study with potential participants, and the principal investigator followed up with email reminders. Those interested in the study were invited to contact the principal investigator for more information about the goals, expected outcomes, ethical considerations, and informed consent for this research (see Appendix C and D). We used purposive sampling (Campbell et al., 2020) to recruit ten consenting PSMI who met the inclusion criteria. We made sure to give our participants, whom we refer to as co-researchers, ample time to ask any questions they had about the project.

3.3 The PAR Procedure

We chose a research lab in the University as the venue for the PAR meetings. This location was chosen to encourage meaningful conversation and better group participation during the PAR sessions, which occurred once a week for ten consecutive weeks from October to December 2022. Each session was approximately two hours long, and we provided healthy refreshments and an honorarium of $40 per session for each participant to cover their travel expenses and reimburse their time.

3.3.1 Introductory Meeting

Ten participants expressed interest in participating in our study and signed the consent form after contacting the principal investigator. We had an introductory meeting where we got to know each other, discussed the study background, explained the use of participatory methods, and addressed any concerns or questions from participants. We built a strong partnership between the researchers and co-researchers based on trust and shared experiences. Participants shared openly and stayed engaged, discussing study expectations and group norms. The second through tenth sessions involved engaging the co-researchers in the various steps in the action research cycle.

3.3.2 *Identifying the Problem*

Our first three meetings were aimed at understanding crucial challenges that people with lived experience face in finding and maintaining a job. The group identified numerous hurdles in finding and remaining employed, such as feeling unsafe in the workplace, difficulties in disclosing their illness, and requesting accommodations that hinder job retention (see Appendix E). The group members agreed that stigma is the underlying challenge impacting their job retention and career advancement. The research question we collaboratively developed was, "How do we sustain our jobs?" Throughout the PAR sessions, participants had the opportunity to take on various roles, keeping track of the key points shared during each discussion. All materials developed and discussions during the ten sessions were photographed, recorded, and shared with the group for reference during subsequent stages and for data analysis.

3.3.3 *Deciding and Implementing the Action Steps*

In the third meeting, the group described their experience of stigma at work and their understanding of an emotionally safe work environment. This enabled us to explore possible solutions to reduce stigma and create a supportive work environment. We agreed on education, advocacy, and collaboration as key strategies for long-lasting social change.

Over the fourth and fifth meetings, the group decided on three action plans they worked on from the sixth through the tenth meetings. Firstly, they created a digital success story for the purpose of employer education. Secondly, they reached out to other community organizations for collaboration. Thirdly, they decided to establish a peer-led website to support peers facing workplace challenges.

In our seventh and eighth meetings, the group began implementing the action plans described above. As the first step, they created a digital story series showcasing their

workplace success experiences. These stories highlighted the crucial role of their employers in fostering a supportive work environment and providing accommodations that allowed them to leverage their strengths effectively. The group also initiated networking and website development. However, due to the time-intensive nature of these steps, they could not complete them within the ten-week research period. To address this, the group planned to evaluate and refine each action step when reconvening the following year. This approach allowed them to continue their progress and build on the momentum of their initial efforts, ensuring a more comprehensive and successful implementation of their action plan.

3.3.4 Evaluating the Action, Participatory Data Analysis, and Reflecting on the Outcomes of the Action

The group discussed and recorded specific ways to evaluate the effectiveness of each of their action steps, as described below.

1. **Digital Story.** After completing the digital story series, the group decided to share it with some of their colleagues and supervisors, requesting feedback regarding the effectiveness of the digital story as an educational resource for employers. They agreed this would be a suitable way to evaluate their action step before sharing it with a broader audience on their website.

2. **Website Development.** The group developed a prototype of the website, including the layout and components for their website. They agreed to develop resources for both peers and employers in the future. Resources for peers would support peers in navigating challenges in finding and keeping jobs. Resources for employers would focus on ways to support employers in understanding challenges faced by people with lived experiences and specific ways to support them in their career journey. The website would be tested on a small target audience for effectiveness before making it accessible to a larger audience.

3. **Collaboration with Like-Minded Organizations.** Group members developed

    connections with two community organizations that shared similar interests. Among

    these, an organization proposed collaboration to create a peer-led website, while the

    other organization extended an invitation to co-host an event focused on raising

    awareness about the mental health concerns of employees. The group agreed to act on

    these initiatives when reconvening the following year.

3.4 Measures to Empower the Co-Researchers

One of the main goals of our participatory action research project was to build

capacity and empower our participants. A few measures that we used to empower participants

based on previous research (Chen & Krupa, 2018) were listed below: (1) We helped increase

their personal capacity through equal power sharing throughout the research and supported

them as they took on new roles and made decisions regarding the steps in the action research

cycle. (2) We facilitated better participation in the research process by fostering a

comfortable environment where they felt safe to discuss their concerns with each other freely.

(3) We honored them for the time they invested in research by providing financial incentives

in the form of gift cards, reimbursement for their travel, and healthy refreshments during each

session. (4) We supported the participants throughout the research process to help them build

connections and extend their social support system, leading to new knowledge, skills, and

opportunities. (5) At the end of the study, the participants were supported to discuss their

plans to sustain the peer-support network and to design a website focused on supporting other

PSMI in their career journeys.

3.5 Data Collection

Data collection and analysis were done iteratively through each stage of the research

project. True to the principles of PAR, we completed both the collection of data and the

interpretation of the findings in a way representative of the thoughts and opinions of

participating PSMI. The weekly PAR sessions were audio-recorded and transcribed verbatim. The transcribed data, field notes, and observations made by the research team during the sessions were collected. Co-researchers noted the key themes discussed in each session, and we included a photograph of each session's notes as data during the study. We audio-recorded, transcribed, and anonymized our discussions regarding the problem to focus on, the action steps, and their reflections and deliberations regarding their participation in the action-research cycle. These were collected and labeled based on the session and stored securely throughout the research project.

3.6 Data Analysis

After engaging co-researchers in the ten-week action research cycle, we used thematic analysis (Braun & Clarke, 2006) to identify, analyze, and report patterns within our data. The data we gathered included transcribed accounts of the PAR sessions, the key themes recorded by the participants for each session, and the memos and notes recorded by the research team during the study. We adhered to the six steps described by Braun and Clarke (2006) in our thematic analysis: (1) Familiarization with the data, (2) Generating initial codes, (3) Searching for themes, (4) Reviewing themes, (5) Defining and naming themes, (6) Producing the report.

Following the completion of the research project, the lead researcher followed steps one through five, listed above, and identified initial themes that arose from the group's conversation about their work experiences. The research team used the person-environment occupation model as a framework to categorize the co-researchers' experiences of job search and retention. The team presented the findings to the group for member checking to ensure that all viewpoints were captured and the themes represented their collective experience. We modified our analysis to reflect the changes suggested by the co-researchers.

3.7 Ethical Considerations

The University of Alberta Research Ethics Board approved this project. (See Appendix A for their statement of approval). We discussed the ethical implications of participatory action research with all our co-researchers. All research team members were healthcare professionals and were alert to the potential for emotions, such as grief, frustration, and guilt, that may emerge during discussion and had resources available to support participants during this time. At the beginning of the research, we encouraged our co-researchers to notify us regarding their preferred support resources we could access during a crisis. Co-researchers were informed about the goals, expected outcomes, and potential challenges that may arise during the project. They had the opportunity to consent to participation in the study, regarding anonymization of any identifying information, for the recording and transcribing the discussions and the themes generated during the project, and regarding publication and presentation of the study results. In order to facilitate efficient communication within the research team, we also asked for their consent to use email communication.

3.8 Strategies to Ensure Methodological Rigor

Rigor in qualitative research refers to the quality and trustworthiness of the research findings. In the big-tent criteria for qualitative research, Tracy (2010) outlines eight criteria that signify high quality in qualitative research: the worthiness of the chosen topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence. We explain below how we strived to adhere to these guidelines:

- Worthiness of the topic: We chose our research topic because of its relevance to our PSMI co-researchers.

- Rich rigor: In phase one, we collected relevant data related to our area of research. We also conducted a scoping review to understand how our research approach has historically been used to empower PSMI.

- Sincerity: As the principal investigator, I maintained an audit trail and a reflexive journal throughout the research. This practice helped me ensure honesty and transparency.

- Credibility: We have ensured the credibility of our findings by providing a detailed description of our research process and by grounding our discussions and findings in the diverse context of our co-researchers. Member-checking our findings with our co-researchers ensured that our themes resonated with their collective experience.

- Significant contribution: We believe our research adds value to the existing PAR literature. This is supported by our co-researchers' expressed interest in continuing our meetings beyond the research period.

3.9 Managing Challenges Faced During This Research

Based on the results of our scoping review (Thomas et al., 2023), we anticipated some process-related and personal challenges that the co-researchers might face during the PAR process. Strategies to mitigate these challenges include:

3.9.1 *Managing Process-Related Challenges*

Previous studies have identified a significant challenge of high participant attrition rates. This has been linked to dropouts resulting from symptom exacerbation, incarceration, or work commitments (Karadzhov, 2020). To address this issue, implementing oversampling, ongoing support, and flexibility in the research venue has been recommended to enhance participation and improve study outcomes (Carson Weinstein et al., 2021; Quintas et al., 2013). Our study aimed to recruit ten participants and retain at least 6-8 individuals for all ten sessions. To achieve this, we practiced equitable power sharing, provided ongoing support,

and maintained consistent communication with our co-researchers throughout the PAR process. As a result, we successfully retained eight of the ten co-researchers until the end of the study.

3.9.2 *Supporting Co-Researchers to Manage Personal Challenges*

Previous research shows that some PSMI may face neurocognitive or emotional challenges as they engage in various phases of the PAR process (Schneider et al., 2004). In our study, we anticipated that some participants may face challenges managing their symptoms while also engaging in the research process. To support them, from the beginning of this research, we discussed the research process, including the ethical concerns involved. We supported participants to understand their role as the leaders of the research process. The research team included healthcare professionals, and we created a supportive atmosphere and ensured the availability of adequate resources for support during the PAR sessions. We also created opportunities for casual conversation over refreshments during each PAR session to increase the level of comfort and camaraderie among the participants. Finally, we strived to ensure that the PAR methods used, the interpretation of our findings, and the methods we will use to disseminate our findings align with the interests of our co-researchers, as they are empowered during the research process.

3.10 Final Deliverables

Our research aimed to support PSMI in developing a sustainable network to support each other in adapting to the demands and challenges in their career journey. This involved understanding the challenges faced in achieving job tenure and collaboratively finding ways to overcome these difficulties. To facilitate a sustainable network, it was imperative that the knowledge gained be made accessible to PSMI in a variety of geographical contexts. In order to facilitate these goals, our study had two deliverables - a peer support network and a website dedicated to supporting PSMI in achieving job tenure and progress in their career.

3.10.1   Peer Support Network

The primary aim of our PAR sessions was to support PSMI in developing lasting connections and expanding their social network comprising of people who can support and whom they can support in their career pathways. The weekly PAR sessions were designed to facilitate co-researchers to develop trusting relationships as they continued to meet regularly. Towards the fifth meeting, co-researchers expressed the desire to continue meeting even after completing the formal research project. Responding to the co-researchers' requests, the research team committed to supporting their regular meetings beyond the designated study period.

3.10.2   Website to Support Job Tenure and Career Progression

The co-researchers recognized that developing a website is a fast and accessible way to share what they have learned, ask for thoughts and opinions, and plan forums to collaborate to improve job tenure and career progression. The research team collaborated with the co-researchers as they took the lead in deciding the website's objectives and layout. Everyone agreed to create the website's content again in the new year. (See the website prototype at **htts://elizabe403.wixsite.com/demo-site.**)

3.11   Co-Researchers' Reflections on the Group Process

In the tenth group meeting, the research team facilitated a group discussion to gather co-researchers' perspectives on engaging in the PAR process. The group expressed gratitude for the mutual support they received, valuing the acceptance and acknowledgment of each member's opinions. Through their active participation in weekly meetings, they felt empowered, fostering a sense of hope for initiating a social movement for change. Many co-researchers highlighted their personal transformations, gaining skills to navigate workplace interpersonal challenges. They also experienced a sense of belonging and renewed confidence

in their expertise derived from their lived experiences. The meeting concluded on a positive note, with the group eagerly planning to continue their collaboration in the future.

3.12 Researcher's Positionality

As the principal investigator in this master's thesis research, my position as a 28-year-old woman of Southeast Asian ethnicity and an occupational therapist with over two years of mental health rehabilitation experience significantly shaped my research interests and perspectives. My work with people with lived experiences in India has ignited a passion for research to empower this marginalized group. Through my professional experience, I have witnessed the positive impact of employment on individuals with lived experience of serious mental illness (PSMI) and firmly believe that the challenges they face are rooted in broader social issues.

I approached this research with a constructivist paradigm, embracing a relativist ontology and a subjectivist epistemology. This paradigm allowed me to collaborate with PSMI co-researchers to co-construct solutions to the challenges they encounter in sustaining their jobs. In my interactions with our PSMI co-researchers, I positioned myself as a researcher with an occupational therapy background dedicated to empowering PSMI, drawing on my own experiences of supporting individuals with lived experience of mental illness within my family. As an international student learning about research and mental health rehabilitation systems in Canada, I humbly positioned myself as a budding researcher, eager to learn from our co-researchers' expertise through lived experience. I feel this approach helped bridge any perceived gap between us, fostering a collaborative and equitable relationship. I also believe this created a reciprocal dynamic that helped us engage as peers, valuing each other's knowledge and input. I felt rewarded as our co-researchers actively contributed suggestions and shared their lived experiences, guiding the direction of our research and decision-making processes.

Chapter 4: Findings

The primary outcome of this research project was the creation of a peer-support network aimed at helping peers retain their jobs and advance their careers. The findings are presented in two parts, focusing on the group dynamics that led to the development of the peer-support group and on the main themes discussed during the meetings. The first section details how the ten co-researchers progressed through the steps in the action-research cycle over the course of ten weekly meetings. The second section presents the main topics covered during the meetings, which centered around the co-researchers' experiences with job searching and retention. We used the person-environment-occupation model (Baptiste et al., 2017) as a framework to explain the complex interplay between environmental, work-related, and personal factors that impact job searching and retention experiences for PSMI.

Participant Profile

The group of participants is described using pseudonyms in Table 1. They include five men and five women aged 45-60 years. We referred to group members as co-researchers and collaboratively engaged in identifying challenges and solutions for improved job tenure and career advancement in PSMI.

Table 1. Participant demographic profile (N = 10).

Name	Gender	Age	Work Status & Profession	Participation
Meg	Woman	51	Part-time, Peer-Navigator	Engaged in 9 sessions
Nella	Woman	48	Full-time, Peer-Worker	Engaged in 9 sessions
Pam	Woman	58	Part-time, Retail	Engaged in 8 sessions
Lily	Woman	52	Part-time, Intern	Dropped out in the 3rd session
Holly	Woman	60	Part-time, Retail	Engaged in 9 sessions
Noah	Man	49	Full-time, Executive role	Engaged in 6 sessions
Greg	Man	59	Part-time, Peer-worker	Engaged in all 10 sessions
Andy	Man	59	Part-time, Inventory staff	Engaged in 9 sessions
Ray	Man	58	Part-time, Casual labor-street cleaning	Dropped out in the 4th session
Sam	Man	45	Part-time Security guard.	Engaged in 8 sessions

Some co-researchers were already acquainted with one another through their involvement in activities at a local clubhouse and recovery courses offered by the recovery college. From the time spent at the clubhouse, Greg and Andy developed a strong friendship, often joined by Holly, Sam, Pam, and Lily. Meg held a significant role as a peer navigator and facilitated programs such as the Wellness Recovery Action Program (WRAP) and her own course, Journey to Wellness. Nella worked as a peer support worker at a regional healthcare service. Some co-researchers had obtained employment through an organization where Noah was CEO. As illustrated in Figure 2, the group members gradually got to know each other over 10 weeks, eventually forming a cohesive team focused on the shared objective of reducing the stigma associated with mental illness and promoting inclusive workplaces.

4.1 The PAR Process - The Action Research Cycle and Group Development as a Transformative Process

The group progressed through the steps in the action-research cycle. The co-researchers gradually began to know and trust each other as they worked together to identify and suggest changes to reduce workplace stigma. Over the ten weekly meetings, co-researchers progressively reached a sense of group maturity. As they went through the transformative group process, the group demonstrated characteristics of Tuckman's stages of group development (Tuckman & Jensen, 2010). The co-researchers also experienced several group therapeutic factors (Yalom & Leszcz, 2020). We have described each step in the action research cycle below and the corresponding transformation the group members experienced during each step (See Figure 2 and Table 2).
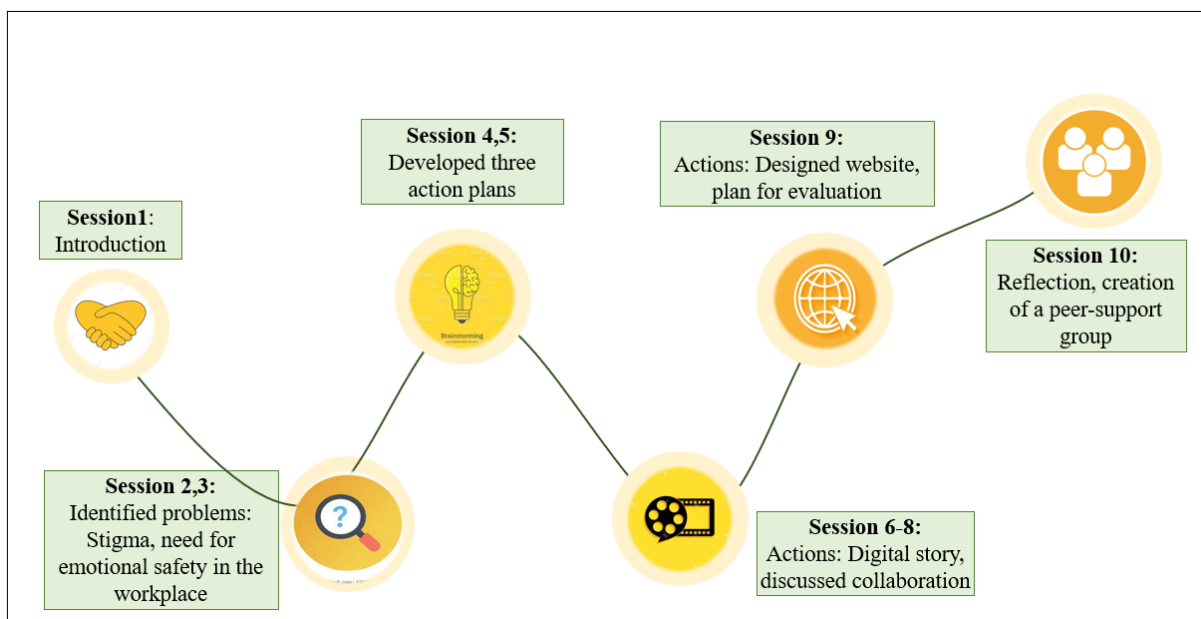
Figure 2. Steps in the Action Research Cycle Over Ten Sessions

Table 2. Steps in the Action Research Cycle with Corresponding Stages of Group Development.

Action research cycle	Group development process		
	Significant milestones	Group Leadership	Tuckman's stage
Step 1: Identifying the problem (Sessions 1-3)	- Developing relationships and group norms - Establishing a common understanding of stigma as a challenge in sustaining employment - Identifying the research question	The research team took the lead in - Organizing meetings - Ensuring consistent communication - facilitating the discussion Co-researchers took on roles such as co-facilitating groups and taking notes.	Forming stage
Step 2: Developing and implementing action plans (Sessions 4 – 8)	- Exploring possible actions to reduce stigma - Planning key actions - Completing three actions	Co-researchers took the lead in two actions: - Creating a digital story - Collaborating with similar organizations	Storming, Norming stage, and performing
Steps 3-5: Evaluating, Analyzing, and Reflecting on the Outcomes (Sessions 9 – 10)	- Developing a plan to evaluate the actions - Developing plans to sustain the group in the future	Co-researchers took the lead in - Deciding ways to evaluate action plans - Ways to sustain the group in the future	Performing stage

4.1.1 Step 1 - Identifying the Problem

In the first three sessions, we worked together with the co-researchers to develop relationships, establish group norms and working practices, and come to a common agreement that stigma is a significant challenge in sustaining employment. This time marked the forming stage of the group's development, and the research team supported the group by taking the lead in organizing the weekly meetings and communicating the goals and notes for each meeting. We have elaborated on these significant milestones and group leadership below.

Significant milestones achieved include:

1. **Developing Relationships.** During this research project, the initial introductory meeting allowed the group members to familiarize themselves with one another and understand the group's purpose. We planned for each meeting to begin with a casual time of refreshments when co-researchers shared their experiences at work over the week. This strengthened existing relationships and developed new connections, creating a supportive environment for sharing concerns as the meetings continued.

2. **Establishing Group Norms.** The co-researchers collaboratively set group norms, including the importance of maintaining confidentiality regarding shared experiences. Some co-researchers actively contributed to shaping the group norms by demonstrating acceptance and support for one another. The group fostered a non-judgmental atmosphere, encouraging open sharing of thoughts. Co-researchers actively shared their experiences and took turns noting key themes discussed in the group discussions.

3. **Establishing a Common Understanding of the Issue.** As the group shared their experiences of finding and maintaining jobs, the co-researchers identified several barriers to sustaining their job. Through their discussions, they agreed that stigma was

a crucial underlying factor that led to a psychologically unsafe work environment and reduced their job tenure. To guide our future discussion and actions, the group framed our research question as "How can we sustain our job?"

Regarding *group leadership*, during the initial sessions, the research team took the lead in setting agendas and maintaining focus in each session. We encouraged collaborative decision-making through questions like, "What does everyone feel like? What is a good way to put our thoughts down?" As the sessions progressed, the group became more independent, with a few members taking leadership roles in facilitating discussions and note-taking; for example, Meg and Noah utilized their leadership experience to guide discussions effectively. Meg's artistic talent was showcased through a personalized vision board, fostering focus and collaboration (see Figure 3, Appendix F). Meg and Nella documented key discussion themes, sharing them with the group (See Appendix E).

The first three sessions, when the group got to know each other and the research team, were considered the *forming stage of group development.* Their initial interactions were hesitant and focused on how the group could benefit their individual concerns. However, as the sessions progressed, a notable transition occurred from individual concerns to a collective focus on the task at hand. While the group members got familiar with one another, they felt increasingly comfortable expressing differing perspectives. They engaged in open discussions, respectfully disagreeing when necessary.

4.1.2   Step 2 - Deciding the Actions

After identifying stigma as a crucial challenge to sustaining employment, in sessions 4-8, the co-researchers explored several strategies to reduce the stigma of mental illness in their workplaces. This included ways to increase awareness of mental illness among employers and to advocate for the employment needs of peers experiencing mental health

challenges. They then prioritized and initiated three action steps to be completed within the ten weeks of this PAR project, which was a ***significant milestone*** achieved in the step.
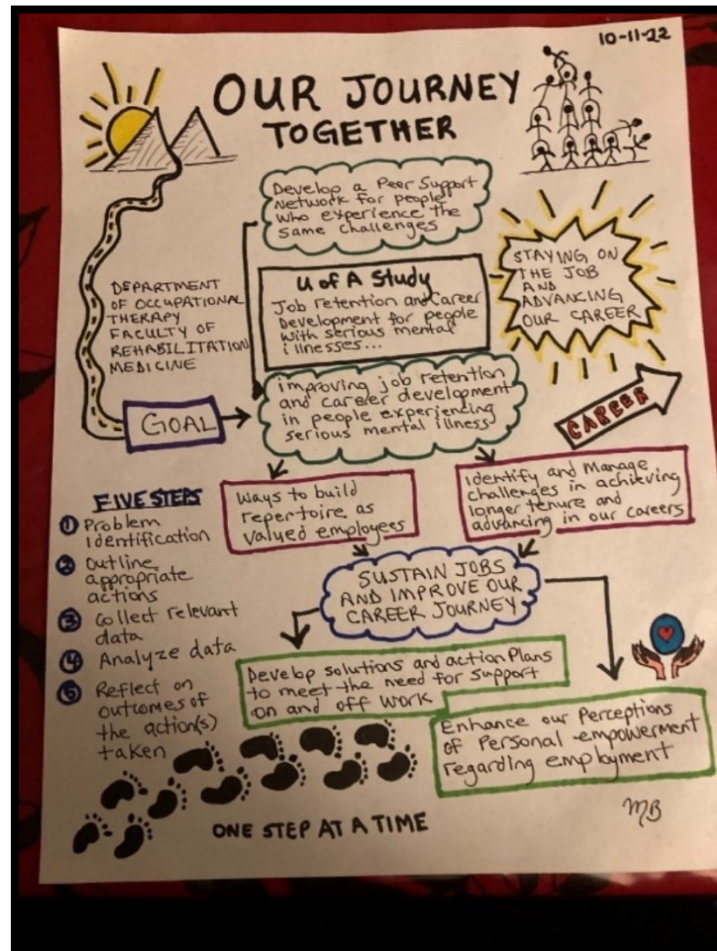
Figure 3. Meg's visual representation of the steps in our research project.

In order to keep us focused as we planned actions to reduce stigma, Meg shared a tool called the *Situation target plan* (See Appendix G) that she developed as a personal recovery tool. This helped the group focus on the problem and operationalize the following three action plans.

1. **Creating a Digital Story.** The co-researchers described the lack of awareness about mental illness as a primary contributing factor to stigma among their employers. They agreed that a digital story was a suitable educational resource to increase awareness about how their employers supported them to succeed at work. Meg and Nella shared their digital stories and guided the group through the steps of creating a digital story. Interested co-researchers created a written script about an experience where they felt supported by their employer. Some co-researchers were apprehensive about recording their voices or sharing their experiences on the Internet. The group addressed this concern, and they were supported to participate in creating the digital story in ways they felt comfortable. For example, at Pam's request, the research team read out the script of her experience. Meg recorded co-researchers as they read their script and guided the group in setting background images and music representative of their experiences. She also compiled their recordings to create an evocative video. In order to keep the video concise, the group agreed to split the video into two episodes, one about supportive employers and the other about accommodation that empowered co-researchers to be successful in their workplaces. (These videos can be accessed at: https://www.wevideo.com/view/3108284258; https://www.wevideo.com/view/3108304223).

2. **Developing a website.** In the fifth session, group members expressed interest in sustaining the group. They recognized the value of creating a website to share employment resources and support peers facing similar challenges in finding and retaining jobs. In order to support this initiative, the research team shared a website prototype (see Figure 4) with the group and facilitated a discussion about the group's ideas for their website. Noah and Meg shared practical insights from their experiences of running a website. Others shared their experiences using websites, providing

strategies to make them user-friendly. Greg suggested 'Get a Job, Keep the Job' as the website's name. Some key features they recommended include the need for a user-friendly format, the resources for the co-researchers to make changes to the website independently, and the need to employ a person to maintain the website. The research team then created a website prototype as per these specifications.

3. **Collaborating with Similar Organizations.** The group recognized the need to work with other similar organizations to widen their reach. Drawing from his executive experience, Noah recommended collaborating with other organizations and promoting existing resources to avoid duplication of services. Meg initiated collaboration with two local organizations catering to Equity, Diversity, and Inclusivity (EDI) in workplaces to achieve this goal. This led to an opportunity for two co-researchers representing the group to attend The Working Stronger conference (https://workingstronger.cmha.ca/conference/), where they developed connections with employers and peers who were invested in creating a supportive work environment. Furthermore, one of the organizations where Meg worked expressed interest in working with the group to sustain the peer-led website in the future.
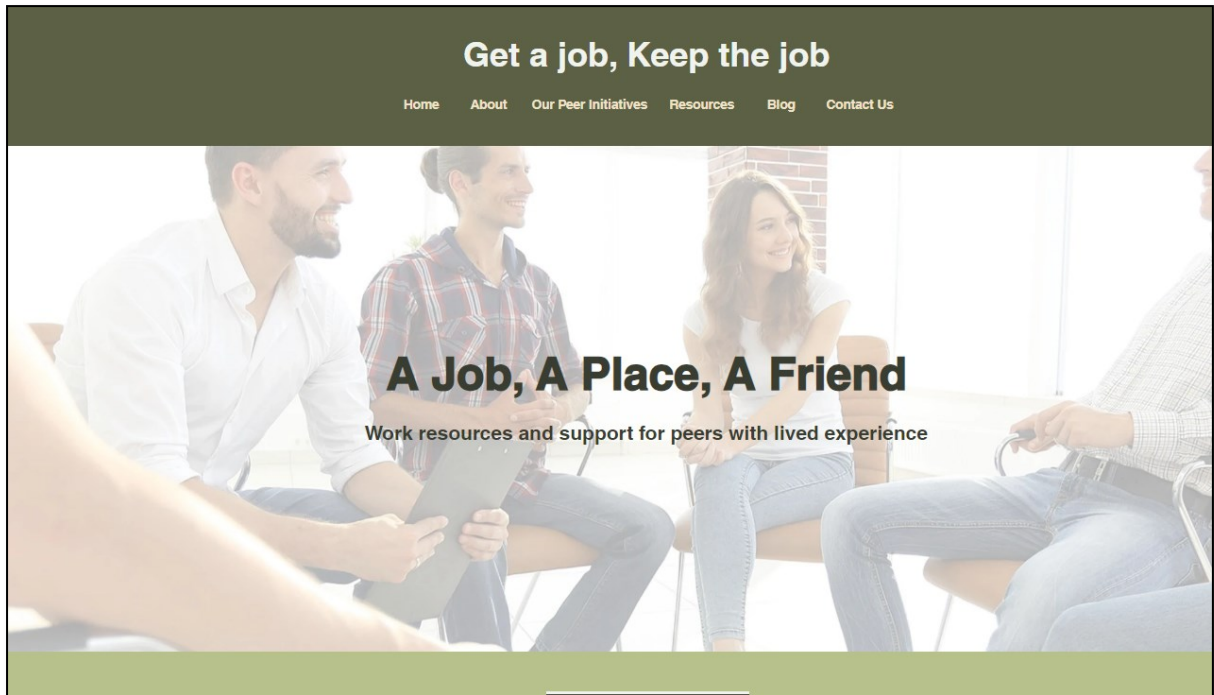
Figure 4. A Prototype of the Peer-Led Website.

In terms of ***group leadership***, the co-researchers start to take on leadership roles and guide the group in taking action to reduce the stigma of mental illness at this step. During the fifth and sixth meetings, the group focused on identifying actionable steps to combat stigma in the workplace. The group members displayed independence by leading the discussion, asking questions to clarify points, and helping each other understand the discussed issues. The group wrote their ideas on stick-it notes, later compiled on a common board (see Figure 5 as an example). The discussion gained momentum as each member's ideas were respected, leading to an optimistic outlook on the potential for social change. Noah steered the conversation to keep the group focused. Meg guided the group in creating the digital story and initiated collaborations with two similar organizations.
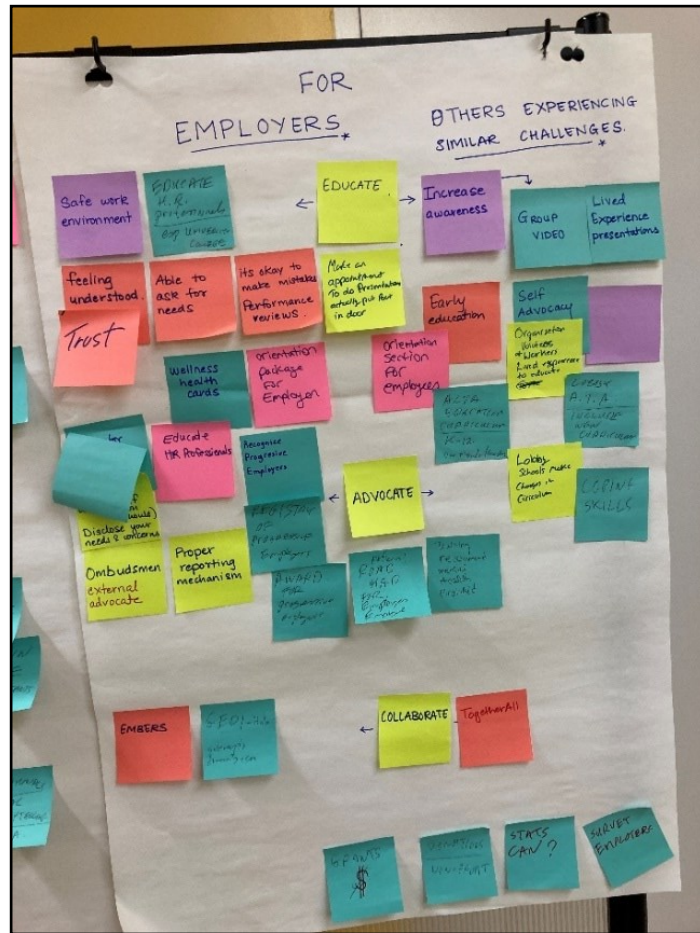
Figure 5. The Group Brainstormed Action Plans to Challenge the Stigma of Mental Illness.

This step demonstrated the ***storming stage of group development.*** During the fourth

through sixth sessions, co-researchers faced interpersonal challenges. Following PAR's core

principles, we followed our co-researchers' lead as they decided the action steps we would

take. Meg, who had previous experience facilitating groups, identified feasible short-term

objectives and established positive relationships with two like-minded organizations.

However, Pam pointed out a shift in leadership dynamics and how some members were

unable to contribute equally in response to Meg's initiatives. This comment caused an

emotional and divided reaction among the group and hurt Meg's feelings. Amidst a tense

atmosphere, Holly got upset with one of Andy's remarks and insisted on an apology, citing

that it undermined PSMI. The research team encouraged teamwork, recognizing the value of

every member's contribution, acknowledging the intensity of the emotions involved, and how

crucial it was for the team to express their sentiments and resolve any conflicts while remaining united.

During the seventh and eighth sessions, the co-researchers formed a cohesive group, progressing to **the norming stage of group development**. The group learned to accept each other's unique personalities and preferences as the group worked collaboratively to create a digital story. For example, Pam actively contributed to the discussion by sharing her experience at work, which the group appreciated and encouraged. Meg welcomed Pam's contribution and supported other members to participate. Working as a team to create the digital story helped the group members improve their communication, express their views, and respectfully handle differing opinions while maintaining a positive and harmonious atmosphere.

4.1.3   Step 3 - Evaluating, Analyzing, and Reflecting on the Outcomes.

The third step in the action research cycle involved evaluating the action steps for their effectiveness. The co-researchers had identified the need to sustain the group and made plans to continue meeting in the new year after a break over the holiday season. They collaboratively developed a plan to evaluate the digital story and to complete the website when they reconvened the following year. The group decided to complete and evaluate the three action plans.

Significant milestones achieved in this step were **developing plans to evaluate the action steps and to sustain the group in the future.** The evaluation plan included a short survey to collect feedback on the digital story with a target audience. The group will make changes based on the feedback before publicizing the digital story on the website. The group discussed the need to spend time developing their mission and vision statement once they reconvened the following year. These core values would be reflected in the layout and content of the website. They plan to collaborate with existing organizations, incorporate links to

resources, and conduct a soft launch of the website to evaluate its accessibility and effectiveness before presenting it to peers and employers.

The co-researchers agreed to meet every other week the following year to sustain the group. The research team agreed to provide the meeting space and help organize the meetings. We were open and honest about the fact that due to funding constraints during this research phase, we would not be able to offer our co-researchers an honorarium or reimburse them for travel expenses. However, we discussed our plan to apply for a research grant together to ensure further sustainability of our group's efforts. The group was very cooperative and expressed their willingness to continue meeting at the current venue, and even offered to share and split their travel expenses. They remained enthusiastic about their plans to collaborate on bringing about social change.

It was obvious that, in the ninth and tenth sessions, the group went through ***the performing stage of group development***. The group worked together to problem-solve challenges in creating the digital story and website. Members adapted to the needs of the task at hand and voluntarily took up roles that helped the group complete the action plans, including initiating collaboration, compiling the digital story, and deciding the website layout. The group assumed a structure that was supportive of performing these tasks, with co-researchers taking on flexible and functional positions. The group invested all its attention and energy into the task. At this step, ***group members naturally assumed leadership roles*** as the need arose. When it came time to elect a representative for an upcoming conference on workplace mental health, Greg was unanimously chosen. Looking ahead to future meetings, we encouraged group members to consider taking on leadership roles and establishing a formal governance structure. While some were open to the idea, there was a general reluctance to commit to long-term leadership positions. During the discussion, Andy shared his belief that some individuals possess more excellent capabilities than others and that he

sometimes struggles with memory. Ultimately, the group agreed that, for the time being, it would be best for the research team to continue organizing meetings for a few more months before developing a formal governance structure.

4.1.4   *Benefits of the Group's Transformation*

The co-researchers experienced numerous therapeutic factors (Yalom & Leszcz, 2020) as they worked together towards their shared goal, leading to a transformation into a cohesive unit. These benefits included the sense of universality, the instillation of hope, catharsis, altruism, and interpersonal learning. The co-researchers found universality in their shared experiences, instilling hope for positive change. Group members connected through shared experiences, such as the consequences of disclosure, mistreatment by employers, medication side effects, and self-care strategies. By sharing their experiences, co-researchers instilled hope in each other, realizing the potential for personal and work-related transformations. They also experienced catharsis, finding solace in each other's struggles and celebrating their successes. Altruism flourished as they supported one another in various aspects, from job searching to accessing financial resources. Interpersonal learning enriched the group as members shared their expertise and collaborated effectively. Each co-researcher contributed unique insights, such as Meg and Nella's guidance in digital storytelling, Noah's employment services expertise, and Meg's sharing of the resources she created to enhance her wellness (see Appendix H). The group's journey highlighted the power of cooperation and mutual support in achieving their goals.

4.2   New Knowledge Generated – Factors Influencing Job Tenure

The following section highlights the key themes discussed in the 10 sessions, focusing on the co-researchers' personal experiences finding and maintaining a job. The co-researchers identified three main areas that interacted dynamically to influence their workplace

participation: Environmental, personal, and work-related factors. We, therefore, utilized the Person-Environment-Occupation (PEO) model (Baptiste et al., 2017) to illustrate the intersection of these factors, representing the degree to which a job aligns with an individual's capabilities (see Figure 6). This intersection influences the level of mutual reciprocity between employers and employees, as well as their productivity in the workplace. Below, we further elaborate on each of these factors and their impact on the co-researchers' job tenure.
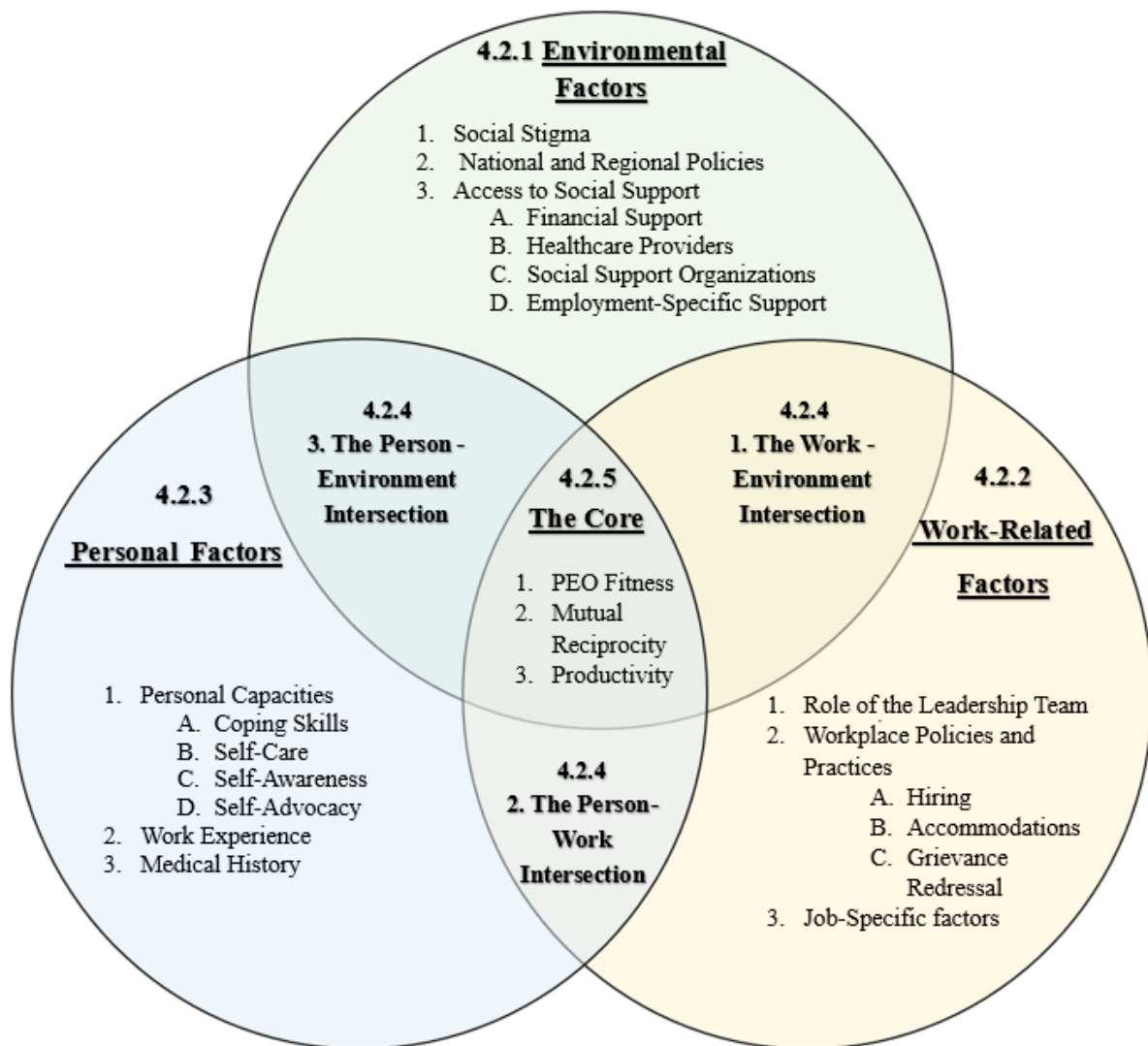
Figure 6. Factors Influencing Job Tenure in People with lived experience of Serious Mental Illness.

4.2.1 *Environmental Factors*

Environmental factors, such as socio-political factors, funding policies, and access to support mechanisms, play a significant role in an individual's ability to find and keep jobs. These factors are beyond an individual's control but directly and indirectly impact their experience. The effects of environmental factors are complex and constantly changing. For example, policies that provide financial assistance to individuals with disabilities, like Assured Income for the Severely Handicapped (AISH), can unintentionally limit their work hours to maintain funding. Additionally, negative attitudes and behaviors towards people with mental illness due to stereotypes can have subtle yet harmful effects. The co-researchers have identified three environmental factors that influence their work experiences and job tenure:

1. **Social Stigma.** In our discussions, the topic of maintaining employment sparked discussions about various challenges our co-researchers faced. These challenges encompassed biases against individuals with mental illness, apprehension about disclosing mental health issues at work, difficulties in seeking accommodations, and a lack of awareness about the lived experiences of those with mental health challenges. As the discussions unfolded, the group recognized that these challenges stemmed from a common underlying issue: the stigma surrounding mental illness. For example, Andy aptly described workplace stigma, emphasizing that those in higher positions hold the power to label individuals, which often leads to differential treatment, causing significant concerns. The key challenges discussed by co-researchers about stigma included stereotypes about people with mental illness, the pervasiveness of stigma in healthcare services, and the pervasiveness of stigmatizing terminology. Each of these has been elaborated on below.

   A. ***Stereotypes About People with Mental Illness.*** The co-researchers observed that mental illness, being invisible, is often not recognized as a disability,

leading to stereotypes. Social media portrayal of people with mental illness as incompetent or dangerous further perpetuates these stereotypes. Limited contact with PSMI in society causes people to form opinions based on social media content. While the group acknowledged that broader societal elements, including entertainment, are beyond their control, they acknowledged that these factors impact their work experiences and contribute to the stigma of mental illness. During the discussion, Lily described stereotypes as the assumption that a diagnosis of mental illness automatically renders individuals incapable. Nella expanded on this, emphasizing that each individual's experience with mental illness is unique, and generalizations fail to consider their individuality. The group recognized that mental illness remains taboo and poorly understood by many. To address this, they proposed incorporating mental health discussions in school curricula to raise awareness and normalize conversations about mental health care.

B. ***The Pervasive Stigma of Mental Illness within the Healthcare System.*** Stigma remains a significant challenge within the healthcare system, as it manifests in healthcare providers' policies, attitudes, and behaviors toward individuals with mental illness. Nella, a peer-support worker, shed light on the persistence of stigma even within the mental health care field. Reflecting on her experiences, she shared, "Despite being employed to utilize my lived experience, I still encounter stigma. Evidently, we have much progress to make in addressing this pressing issue."

C. ***The Pervasiveness of Stigmatizing Terminology.*** The co-researchers described the prevalent use of stigmatizing terminology in legislative forms and medical documents. Ray shared his personal experience of feeling

stigmatized while completing the application for government financial support. Similarly, Pam expressed discomfort with the term "modified work" used by The Workers Compensation Board (WCB) of the province to describe returning to work after a disability leave. She highlighted how such language might imply diminished value or replaceability. The group collectively recognized the significance of using empowering language, especially during the transition back to work after a mental health episode, emphasizing the importance of "modified work" in a positive light to support individuals in their recovery journey.

  While acknowledging the progress made in mental health stigma discourse over the years, the group realized the need for continued advocacy to change societal attitudes and behaviors towards those with lived experience of mental illness. As a result, they dedicated their research efforts to combatting stigma, considering it a critical challenge deserving of their attention and commitment.

2. **National and Regional Policies.** Though this environmental factor did not emerge during the ten PAR sessions, the co-researchers highlighted the significant influence of national and regional policies on their ability to acquire and maintain employment during the member-checking exercise. Noah, who possesses expertise in the employment sector, emphasized the crucial role played by policymakers' attitudes toward individuals facing barriers to employment. These attitudes directly impact the continuity of funds received by employment-support organizations, subsequently affecting the level of support and services available to individuals with barriers to employment in their quest to secure and retain jobs.

3. **Access to Social Support.** The group discussed the benefits of social support in increasing their capacity to balance recovery with their career journey. They understood social support as guidance and resources to navigate personal challenges they faced, being able to openly speak about the unique situations they encountered with stigma and guidance regarding new resources at work. They valued social support in the form of friendships with peers, supportive relationships with healthcare providers, and guidance from employment-specific support organizations. Four types of social support were discussed:

   A. ***Financial Support from the Government.*** Several co-researchers mentioned receiving financial assistance from the government, which helped them purchase their medication and supplies. Ray shared that he initially hesitated to apply for financial aid, and it took him three years to complete the application process and receive the funding. Lily also stated that the application process was lengthy and time-consuming. Many co-researchers agreed that the bureaucratic hurdles linked to the financial support system, such as the use of stigmatizing language in the application form and the prolonged review process, made it difficult for them to receive the support. Noah pointed out that while the funds were beneficial, they also prevented PSMI from working more than a certain number of hours to avoid a reduction in their funding. He observed that many PSMI preferred not to give up the support due to its importance in the event of an acute mental health episode, which could impact their work and income.

   B. ***Support from Healthcare Providers.*** Ray recognized his occupational therapist's vital role in helping him understand his diagnosis, symptoms, and the availability of financial support. Initially hesitant, his perspective shifted,

realizing the importance of living decently while searching for the right path. Furthermore, he highlighted the value of ongoing support from an occupational therapist while navigating work challenges. Unfortunately, the loss of this support led to him leaving his job after a few years. Similarly, Greg appreciated a psychiatrist supporting his dream of owning a motorcycle.

C. *Social Support Organizations.* Most co-researchers actively engaged in recovery-focused activities at a clubhouse and community-based organizations. This provided them a supportive environment to connect with peers, learn about various aspects of their lives, and gain work experience. Social activities at the clubhouse also facilitated new connections and served as a valuable resource for securing jobs. For example, Andy received assistance to develop a resume; Greg found work references; and for Noah, the peer group in the organization became a safe space to discuss challenges and receive support openly. Peer support played a crucial role in navigating workplace challenges.

D. *Organizations Providing Employment-specific Support.* Community organizations that assist employees with employment barriers were identified as a valuable resource for navigating career paths. One such organization is Gateway Association, funded by the government and specializes in connecting employers and promoting Equity, Diversity, and Inclusion (EDI) in the workplace. With a database of over 10,000 employers and a website full of resources, Gateway Association supports employers in enhancing EDI. During workshops offered by these organizations, some co-researchers developed their computer skills and created professional resumes using LinkedIn to aid in their job search. Another organization, Onsite Placement (OSP), advocates for

employment opportunities, bridging the gap between job seekers and

employers by prioritizing diversity and inclusivity. As per Noah, an executive

at OSP, the organization also supports occupational health and safety and

serves as a representative for mistreated clients. Co-researchers expressed

gratitude for OSP's assistance securing jobs and appreciated their unbiased

approach. The group unanimously recognized OSP as a vital source of

connections and resources for their professional journeys.

4.2.2 *Work-Related Factors*

The co-researchers discussed three work-related factors that influenced their work

experiences: A leadership team was described as having a pivotal role in setting norms

regarding inclusiveness at the workplace. Secondly, policies and practices regarding hiring,

grievance redressal, accommodations, and opportunities for career advancement influenced

the level of comfort the co-researchers experienced at work. The third factor comprised

factors specific to the nature of the work that co-researchers engaged in. We have elaborated

on each of these work-related factors below.

1. **The Role of the Leadership Team.** The co-researchers unanimously recognized the

   leadership team's crucial role in shaping workplace culture. They emphasized that

   supervisors and bosses influence whether a workplace is toxic or accepting.

   Leadership plays a significant role in creating a supportive work environment,

   providing support mechanisms during crises, arranging accommodations, setting clear

   expectations, and building trust with employees. For example, Sam described an

   experience where his employer followed up with him while he was in the hospital

   after a mental health crisis, making arrangements for him to return to work on a part-

   time basis. He said, "… that's when I realized I was valuable, and my employer

   wanted to keep me." Supportive leadership helped co-researchers navigate challenges

and fostered a sense of safety and acceptance. However, some co-researchers faced challenges with leadership's lack of trust, unfair handling of grievances, and biases against mental illness. Another example where employers demonstrated a lack of trust in their employees was when the employer would "hover" over an employee, creating a toxic work environment. Greg described this: "There are several occasions where that boss would hover over me. He would stand behind me when I was doing something, you know, watching everything that I did." The group also mentioned that biases against mental illness often led to negative responses from the leadership team towards those with lived experience. The onus lies on employers to initiate open conversations about mental health and create a psychologically safe environment. This approach benefits all employees, irrespective of formal diagnoses, and fosters positive workplace experiences.

2. **Workplace Policies and Practices.** The policies and practices in a workplace are influenced by the organization's goals and values, which, in turn, influence their attitudes toward inclusivity. The co-researchers spoke about the influence of workplace policies regarding hiring practices, provision of work accommodations, and grievance redressal as factors that influenced their experiences of staying on the job.

   A. *Hiring Practices.* Hiring and interviewing are crucial aspects of the job search process. However, standard hiring practices can pose challenges for individuals with barriers to employment, often resulting in marginalization and exclusion from corporate organizations. Noah emphasized the need for employers to understand that specific skills, like catching spelling mistakes or interviewing well, may not necessarily reflect a person's ability to perform a job. He suggested that employers should engage in open conversations with

potential employees, discussing their strengths and weaknesses instead of immediately dismissing them based on traditional hiring practices. Ray stressed the importance of trust in the hiring process, particularly when it comes to disclosing mental health issues. To enhance PSMI's experiences of hiring practices, employers need to adopt more inclusive approaches that value individuals' skills and strengths beyond traditional criteria. Organizations can attract diverse talent and create a more equitable workplace by fostering a more inclusive and understanding hiring process. Ultimately, both employers and job-seekers can benefit from a more inclusive and open hiring process.

B. *Accommodations.* Several co-researchers found that adjusting their work schedule or environment increased their productivity at work. For example, Andy shared his experience of requesting accommodation at his previous workplace. He needed to avoid working early morning hours due to his sleep disorder. His supervisor was understanding and allowed him to work mainly in the afternoons. Andy explained that employers who do not have experience working with employees with disabilities or barriers to employment might not be as accommodating. Ray mentioned that some employees may hesitate to ask for accommodations, such as a mental health day, due to fear of stigma. Additionally, Noah cautioned the group about asking for accommodations, pointing out the possibility that some employers might gradually fire an employee who requests accommodations, making it difficult for the employee to prove discrimination.

C. *Grievance Redressal.* Several co-researchers acknowledged that interpersonal challenges and grievances are typical in workplace relationships. They admitted feeling more vulnerable because of their experiences dealing with

such challenges at work. Most of them were uncomfortable reporting their grievances to their employers due to fear of losing their jobs. Andy expressed his worry about the lack of protection for employees who express grievances and continue to suffer from unfair treatment. Noah also agreed and suggested the need for proper reporting mechanisms for effective grievance redressal. They preferred their employers to acknowledge their grievances and take necessary actions to address them. They also recognized the need for an escalation process to consider the grievance on several levels. They also acknowledged that smaller organizations might have fewer resources for grievance redressal than larger ones. Sam recommended the need for a mental health advisor, an unbiased resource person who would support both employers and employees with concerns regarding mental health or mental illness. All co-researchers agreed on the benefits of an external advocate to mediate the rights and needs of people with lived experience when resolving grievances.

3. **Job-Specific Factors.** Job-specific factors significantly impact work experiences, as revealed in our discussions with co-researchers holding various positions, such as casual, part-time, and full-time jobs. The specific tasks demanded by the job and their alignment with individual abilities played a significant role in co-researchers' job retention experiences. Sam found his job at a local transit station stressful and unpredictable, leading him to consider seeking alternative employment. Greg felt treated like a machine in his family's concrete business, experiencing harsh criticism for any mistakes. Nella wished to share her recovery journey from mental illness with peers. However, she was constrained by regulations deeming it unprofessional in her previous employment setting, which prompted her to switch to her current role as a

peer-support worker. In contrast, despite not being full-time, Ray found satisfaction in his casual street cleaning job due to its stress-free and sustainable nature.

4.2.3   *Personal Factors*

Various personal capacities influenced the co-researchers' work experiences. For instance, coping skills, self-care practices, and self-awareness were crucial for managing workplace challenges and well-being. Some co-researchers faced self-advocacy challenges, underscoring the importance of assertiveness for workplace success. Professional networking shaped their perceptions of work and job performance. Co-morbid physical conditions alongside mental illness influenced their experience of job searching. Medication also played a significant role in their recovery journey, with varying effects on work and overall well-being. These personal factors intersected dynamically with environmental and work-related factors and influenced job tenure in PSMI. We have elaborated on each of these factors below.

1. **Personal Capacities.** Personal capacities, including coping skills, self-care, self-awareness, and self-advocacy, were identified as key factors that helped the co-researchers navigate their career journeys.

    A. ***Coping Skills.*** Many co-researchers developed healthy coping skills to manage workplace challenges while maintaining well-being. Andy expressed his resilience in the face of life-altering illness and emphasized the importance of seeking support and triumphing over difficulties. Their strategies for coping with workplace stress included setting clear boundaries, seeking peer support, and engaging in mindfulness practices. Ray acknowledged alcohol consumption as a past unhealthy coping mechanism, while Andy found solace in volunteering and peer support. Greg used to listen to a talk show as a

helpful stress management tool, and Noah relied on a peer support group. Effective coping strategies were vital in navigating challenging work situations and finding peer support.

B. ***Self-Care.*** The co-researchers recognized self-care as crucial for work-life balance and supporting others. Greg emphasized self-acceptance, while Meg highlighted the benefits of regular self-care routines, such as swimming and mindfulness practices, in maintaining overall well-being and confidence at work.

C. ***Self-Awareness.*** Meg believed that self-awareness was essential when hunting for a job. Based on her experience as a peer navigator, she emphasized the importance of reflecting on oneself and understanding their preferences, such as which environments they thrived in and which ones they should avoid. Meg also advised job seekers to identify triggers that might negatively affect their work performance.

D. ***Self-Advocacy.*** The challenge of self-advocacy was evident among some co-researchers, who struggled to express their needs at work. Holly pointed out the risks of not being assertive, as it could lead to being taken advantage of at work. Meg demonstrated the benefits of assertiveness in her career success. Assertiveness was critical when requesting support, such as modified work or reasonable accommodations, at the workplace. For instance, Meg's wellness health card (Appendix H) provided practical ways for employers and colleagues to support her during mental health crises, fostering a more respectful and supportive work environment.

2. **Work Experience.** Co-researchers discussed how past work experiences influenced their perception of work and job performance. Networking was highlighted as crucial for career success, with Noah sharing his experience of gaining professional connections through networking events. Ray and Greg expressed how previous experiences affected their confidence in finding suitable work. The co-researchers also discussed feeling taken advantage of, leading to frustration and job dissatisfaction. Lack of autonomy was a concern, as Greg and Andy felt decisions were made by their employers without their input. On the other hand, Nella appreciated her employer's trust in allowing her to make choices concerning her work, especially during a difficult time in her personal life.

3. *Medical History.* Some co-researchers discussed their physical co-morbidities, including arthritic complications and chronic pain, alongside their mental illness, impacting their job search and emotional well-being. Noah shared how a hypomanic episode led him to start his own business but also acknowledged the challenges it brought. Ray discussed how social anxiety affected his work performance, causing communication difficulties. Medication played a significant role in their recovery journey, with Ray sharing the process of finding the right combination that worked for him. Greg described the adverse side effects he experienced with his previous medication, affecting his social interactions and overall well-being. Similarly, Sam and Nella reported feeling exhausted due to their psychotropic medication, requiring them to plan their work hours at suitable times to function productively despite the medication's side effects.

4.2.4 *Intersection of the Personal, Environmental, and Occupational Factors*

The PEO model identifies the intersection between a person, their environment, and the occupations, including paid employment, that they engage in. These components intersect in various ways, influencing a person's occupational performance and overall well-being. We have described the intersection between personal, environmental, and work-related factors described above in three parts: The work-environment intersection, the person-work intersection, and the person-environment intersection.

1. **The Work-Environment Intersection.** A combination of environmental and work-related factors influenced the co-researchers' workplace experiences. Social stigma, combined with a lack of social support, impacted co-researchers' job prospects. Perception of PSMI as incapable affected their ability to find and keep jobs in performance-driven environments. Bias against PSMI, particularly in the private sector, led to fear of disclosing mental illness at work.

   A. *Workplace Physical Environment.* The workplace environment includes both physical and psycho-social aspects. The physical environment refers to the tangible surroundings present in the workplace, which can vary depending on the nature of the job. Co-researchers faced diverse challenges based on the nature of their physical work environment. For example, Sam's security job at transit stations was challenging, with inconsistent hours and having to handle a drug overdose situation by himself, causing him significant stress and reduced job tenure.

   B. *Psycho-Social Environment: Workplace Culture.* The co-researchers discussed the psychosocial environment within their workplaces, focusing on people's attitudes and behavior toward each other. They recognized the impact of workplace culture and organizational policies on their experiences. For

instance, Pam highlighted the positive atmosphere at her workplace, stating, "I'm lucky that I'm working in a place that is very much like a family. Moreover, you protect each other." Supportive cultures foster positive experiences, but toxic ones lead to frustration and mistreatment. Signs of toxicity include verbal abuse and lack of trust. Toxic workplaces show outright hostility or subtle mistreatment. Microaggressions are pervasive in such environments. For example, Holly expressed her frustration with being taken advantage of by employers and feeling disrespected, explaining, "It is like being walked on like a doormat." It is crucial to address these issues for a positive work environment. The co-researchers underscored the need for organizations to prioritize employee well-being and create psychologically safe environments. By fostering a culture of respect and support, employers can contribute to a positive work environment that enhances employee satisfaction and productivity.

C. *Unfair Treatment of Workers: A Systematic Problem.* Employers prioritizing profits over employee well-being leads to overwork and neglect of mental health. This issue is compounded by the high demand for work in the market, leading to a perception that it is easier to let go of employees who need additional support to perform adequately rather than working to support them. Noah, an executive with experience in the field, believes that this attitude is ultimately more expensive and unsustainable in the long run, as it leads to high turnover rates and the need for constant recruitment and training. Instead, he suggests building genuine relationships and supporting employees enhances productivity and job satisfaction, which is especially crucial for individuals with mental health challenges.

2. **The Person-Work Intersection.** Various work-related factors, including leadership support, accommodation policies, job nature, and workplace culture, intersect with personal elements like life stressors, natural supports, and socio-economic background. Noah pointed out that employees with less natural support might endure job discomfort due to difficulty finding alternatives quickly. As a result, they may not express their challenges, leading to job dissatisfaction and reluctance to leave, even if they feel unsafe or unfulfilled. Co-researchers also expressed distress about disclosing their diagnosis to employers.

    A. *Disclosure.* Several co-researchers expressed concerns about disclosing their mental illness to their employer or colleagues, highlighting the advantages and disadvantages of such disclosure. The group recognized that disclosure could lead to requesting necessary accommodations in inclusive and supportive workplaces but also feared potential job loss or differential treatment. The co-researchers emphasized the importance of timing and establishing relationships before disclosure due to the pervasive stigma surrounding mental illness. Lilly argues that disclosure a few months after getting hired allows the employer to get to know them and may lead to a more favorable outcome, "At least you have had six months, so you got your foot in the door, and they know you before they make that judgment." The co-researchers also shared experiences with the negative consequences of disclosure of their diagnosis, such as judgment and constructive dismissal. Keeping mental health issues private was discussed, with individuals expressing the pressure of hiding their true selves and the challenges of feeling unaccepted. The group agreed that employers should create a safe space for disclosure and offer understanding

without biased judgments. Noah, drawing from his experience, advised waiting until after starting a job to request accommodations. He explained that interviews were already biased, so disclosing a mental health issue could further separate the candidate from the employer's idea of "normal." He also emphasized the crucial role of an inclusive leadership team in fostering a supportive work environment. This would make it easier for employees to discuss their concerns without worrying about negative consequences.

B. *Personal Work Interests.* Co-researchers highlighted how their passions and skills strongly impacted their job satisfaction and tenure. Inspired by a peer's lived experience, Meg pursued peer work and underwent training for the Wellness Recovery Action Plan (WRAP), finding immense fulfillment in supporting others. Greg aimed to transition to a role as a peer support worker, aligning with his aspirations. Holly expressed her interest in working with animals. Pursuing work aligned with their interests significantly influenced their job satisfaction and role experiences.

3. **The Person-Environment Intersection.** While discussing their employment experiences, the co-researchers often highlighted the advantages of having a strong professional network and support from family and friends in securing and maintaining their jobs. Their socioeconomic status, education, and early access to treatment also influenced their work experiences. Here are a few examples of the benefits of networking and familial support.

A. *Networks.* Noah recognized the significance of his social connections in securing his first job. Through a personal connection already employed there, he landed his initial job. Later, a professional connection led him to a temporary executive director role at an organization, which eventually turned

into his current position. Noah believed that building a personal network was vital for finding employment. He recommended, "It takes time to build a network, but it is a valuable investment for future work opportunities."

B. *Family Support.* The co-researchers shared personal experiences of how their socio-economic backgrounds impacted their work journeys. Nella credited her grandparents' unconditional love for supporting her recovery and achieving her career goals. Having a stable income and family support, she felt fortunate while searching for a job as a peer support worker. Noah and Meg mentioned how their families had supported their career success, while Pam shared her struggles in finding a suitable job and expressed reluctance to cause any trouble, stating, "It took me five years to get this job, and I do not want to rock the boat."

4.2.5   *The Core: Person-Environment-Work Intersection*

According to the PEO model, the intersections between the person, their environment, and work significantly impact their work performance and overall well-being. When these elements are well-aligned, a person's work performance is optimized, increasing satisfaction and well-being. Conversely, a misfit or imbalance between these components can result in challenges in work performance and daily activities. The co-researchers identified three core factors at the heart of the PEO intersection: PEO fitness, mutual reciprocity, and productivity. We will now explain each of these factors below.

1. **PEO Fitness.** According to the co-researchers, finding a job that aligns with an individual's skills and interests is crucial for maintaining employment. They emphasized the importance of a "good-fit" job where the responsibilities and tasks align with their capabilities and interests. Conversely, a poor-fit job can result in stress and dissatisfaction. Andy emphasized the enjoyment of the job and positive

relationships with colleagues as essential factors. Noah emphasized the benefits of employers considering employees' skills and abilities when assigning tasks, leading to improved performance and benefiting both individuals and organizations. Ray described his experience with street cleaning, stating that it provided him with a stress-free and light-duty environment that suited him well. He emphasized that office work was not a good fit for him and that he found fulfillment in street cleaning. Meg discussed her struggle with work-life balance but found that switching to a job aligned with her skills and interests positively impacted her well-being. She found fulfillment and improved health through peer work, her passion. These experiences highlight the importance of finding a job that aligns with an individual's skills, interests, and overall well-being. Such a fitting job can contribute to greater satisfaction, productivity, and overall success in the workplace.

2. **Mutual Reciprocity.** The co-researchers emphasized the significance of establishing trusting relationships between employers and employees to cultivate a supportive work environment. Noah stressed the shared responsibility of both parties in creating such an environment, mentioning, "The employer has to have some understanding of what they can do to help...and the employee is willing to advocate for themselves and work well together - then we can meet in the middle somewhere." This collaborative approach promotes an environment where employees can care for themselves, increasing productivity and decreasing turnover. Nella shared her positive experience with trust within her leadership team, which fostered loyalty and support among colleagues. She expressed her ability to request time off when needed, receiving approval and support from her peers and team members. Nella emphasized her loyalty to her team and willingness to go the extra mile because she felt genuinely cared for by their leadership. The co-researchers' insights underscored the importance of trust

and mutual support between employers and employees. In conclusion, the group recognized that trust, understanding, and support between employers and employees are integral to fostering a supportive work environment. When these elements are present, employees are more motivated, productive, and willing to go above and beyond for the organization

3. **Productivity.** During the data analysis, the co-researchers reflected on the emerging findings and gave thought to the core of the PEO intersection. They contemplated how the interplay of their personal characteristics, environmental factors, and work-related contexts influenced their productivity in the workplace. Recognizing this as a vital component, they highlighted its significance in maintaining harmony among the three elements of the PEO model. At their suggestion, we have included. productivity as an important factor at the core of the PEO intersection.

4.3 Recommendations

The co-researchers devised several recommendations to reduce stigma when discussing challenges due to social stigma. We have presented the recommendations for employers and peers below.

4.3.1   Recommendations for Employers

1. **Increase Awareness.** Employers should actively raise awareness about mental health and the challenges associated with mental illness among their workforce. This can be achieved through workshops, seminars, and educational materials that promote understanding and empathy.

2. **Avoid Othering.** When discussing issues related to mental health, employers should foster an inclusive and supportive environment by using language that avoids stigmatization or othering of individuals with mental health concerns.

3. **Supportive Workplace Culture.** Advocate for and create a supportive workplace culture that prioritizes employee well-being. A workplace fostering support and understanding will likely thrive in the long run, improving productivity and employee satisfaction.

4. **Mandatory Mental Health Training.** Employers should implement mandatory training for managers and staff regarding mental health care and mental illness. This training equips employees with the knowledge and skills to support their colleagues effectively.

5. **Seek External Guidance.** Consider engaging an impartial, external agent who can provide guidance and assistance when dealing with employees facing employment barriers due to mental health challenges. Employees can also benefit from seeking external support to resolve conflicts in the workplace, ensuring a fair and safe working environment for all.

6. **Establish Peer-Support Network.** Encourage the creation of a peer-support network among employees at work. Peer support can provide a safe space for individuals to share experiences, seek guidance, and foster a sense of community and understanding.

4.3.2 *Recommendations for Peers*

1. **Challenge Stigmatizing Attitudes.** Peers should proactively challenge stigmatizing attitudes and behaviors related to mental health in the workplace. Responding with compassion and empathy can help create a more inclusive and understanding work

environment.

2. **Be Open to Questions.** Be open to discussing lived experiences with mental illness if comfortable doing so. Encouraging colleagues to ask questions and seek knowledge can promote awareness and break down misconceptions surrounding mental health.

By implementing these recommendations, employers and peers can reduce social stigma related to mental health in the workplace and foster a more supportive and empathetic environment for all employees.

4.4 Summary - Integrating the Process and the Content

Throughout our participatory action research (PAR) journey, we actively fostered collaborative engagement with our co-researchers, facilitating in-depth discussions during our weekly meetings, where invaluable insights and experiences regarding job searching and the intricacies of employment sustainability were candidly exchanged. Our communication with co-researchers was clear and consistent, underscored by a strength-based approach wholeheartedly embraced and guided by their expert perspectives derived from lived experiences. The research team's endeavors harmonized seamlessly with the pre-existing familiarity among some co-researchers and their shared passion for mitigating the stigma of mental illness. This synergy was integral in fostering a collaborative and supportive ambiance. Regular, consecutive in-person meetings, bolstered by a non-judgmental environment, cultivated a strong sense of trust among co-researchers, emboldening them to address their workplace challenges and provide mutual assistance candidly. This exchange of support nurtured a growing sense of belonging. It gave rise to a platform for co-researchers to develop and implement strategies to combat the stigma of mental illness, a challenge they identified as paramount to job acquisition and maintenance.

Through a dynamic exchange of perspectives, this collaborative approach facilitated the co-creating a comprehensive framework to enhance job retention among PSMI. The five-step action research cycle enabled co-researchers to collectively identify stigma as a key barrier to successful work experiences. Detailed discussions with PSMI about job-seeking and maintenance revealed the complex intersection of environmental, work-related, and personal factors influencing their employment journeys. This revealed the deep-reaching influence of stigma and the catalytic role of supportive workplace leadership. Narratives of both successful and challenging work situations offered a nuanced understanding of these dynamics, fostering a sense of relatability and camaraderie among group members. This, in turn, heightened their enthusiasm for the weekly meetings.

The co-creation of an evocative digital storytelling video featuring their successful work experiences was a tangible action step that empowered co-researchers and invigorated their motivation to enact broader social change. This atmosphere of positivity and creativity significantly fuelled the co-researchers' commitment to the group, leading them to express a resounding desire to continue their meetings beyond the formal research project. Our findings underscore clear evidence that collaborative efforts, as demonstrated by this PAR-driven framework, can lead to successful strategies for improving job retention and well-being for PSMI in the workforce.

Chapter 5: Discussion

The concluding chapter begins with a succinct summary of the study's key findings and primary objectives. Following this, we delve into a comprehensive discussion of how these findings align with the existing literature. Additionally, we address the limitations inherent in the study and present our conclusions, highlighting the implications of our research. Finally, we offer insightful recommendations for future investigations to guide further progress in the field.

5.1 Summary of Findings

This study aimed to empower PSMI to sustain employment using a PAR approach with them as co-researchers. It led to a transformative journey, resulting in a peer-support network dedicated to helping other peers maintain jobs and advance careers. Our co-researchers completed three steps in the action-research cycle during the ten-week research process. They identified three key factors influencing job acquisition and maintenance: environmental, work-related, and personal. They also experienced therapeutic benefits, such as universality, hope, catharsis, and interpersonal learning. The study's outcomes included a peer-led employment resource website, a digital story showcasing work successes, collaborations promoting workplace equity, and a peer-support group for those with mental illness. As the principal investigator, I maintained a reflexive journal to document my experiences, thoughts, and observations throughout the study.

5.2 Researcher's Reflexive Notes about the PAR Process

Maintaining a reflexive journal throughout my PAR thesis research proved invaluable in enhancing self-awareness of my assumptions and preconceptions, which could influence the research outcomes. Regular reflections with my supervisor offered more profound

insights into the research context and opportunities for improvement, such as addressing power imbalances and enhancing communication with co-researchers. Initially, transitioning from being an occupational therapist conducting group therapy to becoming a "co-researcher" role, sharing power, and being actively involved in the process posed some challenges. Balancing my occupational therapist background, personal experiences, and role as an international student, I sought to create a collaborative and equitable relationship with co-researchers, bridging perceived gaps between us. During the initial sessions of learning to share power genuinely, I took the lead in planning and guiding the discussion topics to ensure we followed the agenda I had prepared. I was concerned about potential gaps in conversation and the possibility of a fragmented group due to unclear leadership. To foster effective power-sharing, I had to consistently remind myself to step back and allow the group to take charge of the conversation, letting go of my urge to control it. Gradually, by the fourth meeting, I began to strike a delicate balance, leaning on the group to steer the conversation just as they relied on the research team when they needed facilitation or guidance regarding the research process. The expertise of co-researchers with executive roles further enriched this group dynamic. As the research progressed, we functioned as a cohesive team, respecting each other's opinions and making decisions collaboratively.

Throughout the PAR process, I constantly adapted and made decisions akin to building a plane while in flight. Initially, my thesis proposal outlined completing one action research cycle within ten weeks. However, upon receiving feedback from the co-researchers who expressed their need for a slower pace to develop each action step thoughtfully, I understood the importance of being flexible and responsive to their preferences. This shift in approach led to a reciprocal dynamic, empowering the co-researchers and giving them agency in the research process, which, in turn, yielded positive outcomes, including well-structured action plans and increased hopefulness for the future.

Overall, reflexivity was crucial in critically examining my actions and fostering an empowering collaboration with the co-researchers throughout the PAR project. As we begin the discussion of our findings, we aim to compare our research with similar PAR projects exploring employment in PSMI.

5.3 Discussion of Findings

5.3.1 Comparison of our PAR Study with Other Similar Research

Given the growing popularity of PAR for engaging PSMI in research, several studies have adopted this approach to explore and collaboratively address their employment needs. Certain PAR studies focused on developing a collective understanding of various aspects of employment. For example, Millner et al. (2022) and Torres Stone et al. (2018) explored the significance of employment and work-related losses experienced by PSMI, respectively. Rebeiro Gruhl (2012) conducted a study examining how place influences employment access for PSMI in two communities, leading to the generation of solutions to challenge perceptions and build capacity. Maciver et al. (2013) involved PSMI and vocational service providers in improving vocational rehabilitation services through collaborative guidelines development. Sundar and Ochocka (2009) utilized PAR to explore the ideal employment situation for PSMI, identifying barriers and developing action steps. Their findings aligned with ours, reinforcing the importance of environmental, work-related, and personal factors in influencing job retention. Moreover, our study took inspiration from their action steps, specifically by establishing a job-focused peer support group and promoting stigma reduction through local awareness initiatives. Although these studies share a common objective of understanding and improving job retention in PSMI, our unique contribution to the field lies in our focus on the sustainability of co-researchers' efforts in building a peer-support network, representing a novel approach.

5.3.2 Key Ingredients for Sustainability in PAR Research With PSMI

The sustainability of our peer-support group can be attributed to several key factors. Firstly, we prioritized fostering lasting relationships among members, cultivating a sense of trust and camaraderie within the group. Creating a safe and supportive environment allowed individuals to freely share their experiences and seek assistance without hesitation. Secondly, genuine power-sharing was at the core of our group dynamics, focusing on capacity building and valuing each member as an expert in their own right, leading to collaborative decision-making. Lastly, we recognized the immense value of peer support, which was instrumental in sustaining the group's success and fostering a sense of community among the group members. These three key ingredients are further discussed below:

1. **Establishing Long-standing Partnerships.** In other PAR projects, sustainable partnerships beyond the research phase were facilitated by similar factors (Lindamer et al., 2009). These studies invested time in developing lasting community partnerships, which increased co-researcher engagement, fostered trust, and promoted familiarity (e.g., Agner et al., 2020; Lapadat et al., 2020). Employing various strategies, such as engaging in casual conversations over refreshments during meetings (Delman et al., 2019), utilizing an oval table setup to reinforce equality in discussions (Morgan et al., 2003), and using inclusive language (Skoy et al., 2019; Weinstein et al., 2019), also contributed to sustainable partnerships. Additionally, encouraging open expression of ideas and feelings and promoting understanding and solidarity further enhanced co-researcher engagement (Schneider et al., 2004). For example, a study on recovery and resilience in psychosis effectively involved the PAR Co-Design Team, including PSMI co-researchers, in collaboratively addressing ethical concerns and self-identification (Thai et al., 2021), fostering a safe environment, and sustaining the partnership.

2. **Facilitating Genuine Power-Sharing.** The equitable distribution of power, a fundamental principle of PAR, guided our strategies, aligning with those used in other PAR projects. Key approaches included ensuring adequate representation of PSMI co-researchers on the team (Morton et al., 2022; Michalak et al., 2016), valuing their expertise (Thai et al., 2021), and acting on their recommendations (Davidson, 1997). Transparency in the research process and fostering an informal environment also empowered co-researchers to share their opinions from a position of agency (Agner et al., 2020; Malling, 2013). The early establishment of group norms promoted an open and safe space, enabling co-researchers to be vulnerable and support each other. This led to an equitable distribution of power in our interactions, where each member's input was valued, and their suggestions were implemented (Schneider et al., 2004). Capacity building in co-researchers was recognized as crucial in various studies, reinforcing equitable power distribution and empowering PSMI co-researchers to make informed decisions (Raymaker et al., 2020; Sims-Gould et al., 2017). Engagement in research equipped co-researchers with valuable skills, including research methods, ethics, and leadership (Torres Stone et al., 2018; Tischler et al., 2010). Furthermore, hiring PSMI as paid co-researchers and encouraging co-authorship of publications further promoted equitable power dynamics (Pelletier et al., 2015; Robertson et al., 2020).

3. **Promoting Peer Support.** The value of peer support was pivotal in creating a sustainable environment for our co-researchers. As the group members grew acquainted and accepted each other, they became a cohesive unit, offering mutual support and validation. The peer-support group became a collaborative platform for co-researchers to plan and implement workplace changes. One co-researcher expressed gratitude for the support received during a personal crisis at work,

highlighting the reciprocity of peer support. Group members eagerly anticipated their meetings, where they could share experiences, offer and receive validation, and learn from one another. They celebrated each other's successes and provided support during challenges, taking on roles as friends, mentors, and supporters among their peers. This created a feeling of belonging, loyalty, and camaraderie among our co-researchers. Such positive interactions solidified their commitment to continue meeting and pursuing their shared goal of creating inclusive workplaces.

Numerous studies highlight the significance of peer support in fostering a sense of belonging and normalizing individual experiences among people with similar lived experiences (Suto et al., 2021; Fernandes, 2012). It cultivates mutual support and affirmation, empowering individuals to pursue opportunities beyond the supportive setting (Schneider et al., 2004; Agner et al., 2020). Collaborating towards shared goals in the research process fosters a strong sense of connection among participants (Lapadat et al., 2020), as observed in a community gardening project where PSMI co-researchers found validation and purpose within the group (Suto et al., 2021).

In summary, our peer-support group's sustainability relies on fostering lasting relationships, genuine power-sharing, and the value of peer support. Prioritizing trust, camaraderie, and empowerment led to a cohesive and collaborative environment. Peer support promoted a sense of belonging and mutual affirmation, driving the group's commitment to creating inclusive workplaces. Delman et al. (2019) found that recognizing the research topic's significance, investing in community partners, embracing inclusive leadership, and allowing flexibility were crucial in establishing successful partnerships with PSMI. These insights can guide researchers in developing sustainable partnerships to address social challenges such as mental health stigma.

5.3.3 *The Influence of Stigma on Job Tenure in PSMI*

In our study, the co-researchers emphasized the significant challenge of stigma in their job search and employment experiences, which impacts job acquisition and poses difficulties in job maintenance. Our findings align with existing research, affirming that the stigma sounding mental illness strongly influences the work experiences and overall well-being of PSMI (Krupa et al., 2009; Russinova et al., 2011; Villotti et al., 2018). Previous studies have shown that stigma and discrimination contribute to negative wage differentials and create unsupportive workplace relationships with co-workers and supervisors for PSMI (Krupa et al., 2009). The impact of stigma on PSMI in the workplace can be elucidated through the following aspects:

1. **Understanding Employment-Related Stigma for PSMI.** The stigma of mental illness in the workplace poses a significant barrier to the social inclusion and community participation of individuals with mental health conditions. This powerful process of social control denies PSMI access to important social roles and hinders their full participation and equity in such roles. Sustaining stigma and discrimination are complex processes and not readily observable or interpreted. In an employment-related stigma analysis, Krupa and colleagues (2009) define workplace stigma as a disposition to discriminate against individuals with mental illness, emphasizing its behavioral expression through exclusion from fully integrating into the workforce. To understand the impact of stigma on employment, it is essential to consider exclusion broadly, including discrimination in hiring, promotions, access to employment benefits, equitable workplace policies, and participation in social interactions at work.

2. **Manifestations of Employment-Related Stigma for PSMI.** The stigma towards individuals with mental illness becomes evident in the workplace through discriminatory practices and attitudes. The co-researchers shared their experiences of

encountering micromanagement, unfair treatment, and inadequate grievance handling, which align with previous research. Russinova and colleagues (2011) identified three pathways of prejudice and discrimination: direct expression targeted at individuals with mental illness, indirect expression towards co-workers or clients with mental illness, and perceived or anticipated discrimination. These manifestations have a detrimental impact on individuals' well-being and job experiences. Discriminatory practices can vary from subtle to overt expressions, resulting in hesitancy in hiring or promoting, higher termination rates, and social marginalization. Workers with mental health conditions may experience a disrupted sense of belonging, distress, compromised performance, and potential job loss (Russinova et al., 2011). Co-workers' responses to accommodations are influenced by the nature of the disability, with less visible and self-caused disabilities eliciting stronger negative attitudes, potentially affecting accommodations for workers with psychiatric disabilities (Colella et al., 2004).

3. **Causes and Consequences of Employment-Related Stigma for PSMI.** The stigma surrounding mental illness in the workplace is fueled by negative beliefs and stereotypes, hindering the full integration of individuals with mental health conditions into the workforce (Krupa et al., 2009). Our co-researchers shared experiences of facing such stigma, including assumptions about their competence, safety, and the legitimacy of mental illness. Media portrayals also contribute to negative attitudes, impacting employers' willingness to hire individuals with mental illnesses compared to those with physical disabilities (Russinova et al., 2011). The burden of secrecy and limited collective support further hinder efforts to combat workplace stigma (Corrigan et al., 2001). Such stigma has detrimental consequences for individuals with mental illness in the workplace, limiting their career opportunities and access to training,

ultimately leading to lower wages and perpetuating cycles of poverty (Villotti et al., 2018).

 With their inherently stressful nature, contemporary workplaces exacerbate stigma, viewing mental illness as a barrier to employment. Moreover, a lack of workplace support and understanding leaves individuals struggling alone (Krupa et al., 2009). The consequences of workplace stigma are far-reaching and lead to higher risks of unemployment, underemployment, and precarious employment for individuals with mental illness. This severely limits their opportunities for advancement and personal growth (Villotti et al., 2018). The stigma adversely affects society, for instance, underutilizing the workforce's potential, especially in knowledge-based economies that rely on employees' mental capacities. The stressful work environment intensifies the stigma as individuals fear disclosing their health conditions may affect their job performance. This leaves them to wrestle with whether or not to disclose their condition alone, adding further strain to their work experience (Krupa et al., 2009).

4. **Influence of Stigma on Self-Disclosure in the Workplace.** The prevailing stigma and discrimination against individuals with mental illness in the workplace lead to their reluctance to self-disclose due to fear of adverse reactions and differential treatment (Arboleda-Florez, 2003; Diksa, 1996). This reluctance can result in underutilizing assistance programs and accommodations, potentially affecting job tenure (Peters & Brown, 2009). In a study about employee decision-making regarding disclosure of a mental health diagnosis, their co-researchers considered disclosing during a mental health episode or after a leave of absence to help employers understand and support them better (Toth & Dewa, 2014). However, the fear of adverse reactions often outweighs the perceived benefits. Participants in a study on

PSMI's attitudes toward disclosure expressed concerns about trustworthiness, skills, and abilities when taking time off for psychiatric treatment (Peters & Brown, 2009). Our co-researchers also echo Toth and Dewa's concerns about various negative consequences feared with self-disclosure, such as gossip and potential job loss (Toth & Dewa, 2014). People generally exhibit stronger negative attitudes towards invisible disabilities like mental illness, influencing the disclosure decision (Russinova, 2011). By fostering a safe and empathetic workplace through inclusive policies, we can significantly enhance the likelihood of self-disclosure and the willingness to seek assistance (Peters & Brown, 2009). Our co-researchers emphasized the need for inclusive leadership teams to foster a supportive environment where employees can openly discuss concerns without fearing negative consequences (Chen et al., 2017; Peters & Brown, 2009).

5.3.4   The Key Role of Leadership in Influencing Work Experiences for PSMI

Our co-researchers highlighted the prevalent power imbalance in the workplace, with the leadership team exerting significant influence. Consistent with existing literature, they particularly emphasized the pivotal role of a leadership team in establishing inclusivity norms, which in turn influence whether a workplace cultivates a toxic or accepting environment (Evans-Lacko & Knapp, 2018; Von Schrader et al., 2014).

Supportive leadership was seen as essential in creating a work environment that is supportive, safe, and accepting of individuals with mental illness (Follmer et al., 2020). Such leaders proactively provided support mechanisms during mental health crises, arranged necessary accommodations, and established clear expectations for employees (Skakon et al., 2010). Additionally, they built trust with their employees and demonstrated genuine care and concern for employee well-being (Franke et al., 2014). According to Pischel and Felfe (2023), the significance of leaders' support in mitigating the adverse effects of stigma on

disclosure becomes evident. By prioritizing and actively supporting the well-being of their employees through (1) showing genuine concern for their health, (2) attentiveness to warning signs, (3) promoting open communication about health issues, and (4) engaging in health-promoting practices, leaders serve as positive role models and set a standard of inclusive behavior. As a result, even in organizations where mental health stigma is prevalent, employees are more likely to feel comfortable discussing their mental health concerns openly with leaders, trusting that their issues will be handled with confidentiality.

On the other hand, our co-researchers have raised serious concerns about the adverse consequences of leadership lacking trust in employees, which fosters a toxic work environment. The lack of trust led to excessive monitoring and "hovering" over employees. Such practice decreased confidence and increased stress levels for employees. Furthermore, biases against mental illness were evident in how the leadership interacted with individuals with lived experience, leading to discriminatory practices and harmful treatment. These biases had detrimental effects on the overall well-being and work experiences of individuals with mental illness, corroborating findings from previous studies by Von Schrader et al. (2014) and Skakon et al. (2010).

Our co-researchers stressed the importance of employers initiating open conversations about mental health and taking proactive measures to create a psychologically safe and inclusive environment. Congruently, in a study investigating retention and support for employees with mental illness in five Canadian organizations (Gewurtz et al., 2022), two major themes emerged as indicators of psychologically safe work environments: employers who developed relationship-focussed workplaces and implemented flexible, inclusive work practices helped create a supportive environment for all employees, no matter their mental health status. Our co-researchers' experiences aligned with their findings that respectful communication from employers creates a psychologically safe work environment, allowing

employees to ask for help comfortably. In essence, a leadership team that fosters inclusivity and work practices that promote retention and support for employees benefits all employees, regardless of their mental health status, and contributes to a positive and supportive work culture.

5.4 Insights from Social Role Valorization Theory: Factors Influencing Co-Researchers' Work Experience

Social Role Valorization Theory (SRV) offers valuable insights into the factors influencing work experiences in our study (Wolfensberger, 2011). Environmental factors, such as social stigma, profoundly impact national and regional policies, particularly in funding and access to social support organizations (Corrigan et al., 2001). This widespread stigma directly affects how PSMI are perceived and treated in the workplace. Work-related factors also come into play, as employers and co-workers may engage in discriminatory behaviors, inequitable hiring practices, and unfair grievance redressal measures for PSMI, who may be perceived as less valuable due to their devalued social role (Gühne et al., 2021; Gruhl, 2020; Rebeiro Gruhl, 2010).

Through active involvement in the Participatory Action Research (PAR) process, our co-researchers experienced a transformative collective consciousness that enabled them to recognize and address the issue of social devaluation (Ledoux, 2016). Embracing valued roles as research partners and members of the peer support group, our co-researchers challenged the devaluation experienced by PSMI and strived to create more inclusive and supportive work environments (Wolfensberger, 2011; Flynn et al., 1999).

Through the lens of SRV, our findings illustrate how social devaluation perpetuates barriers in the workplace for individuals with mental illness. By understanding the impact of social stigma and discriminatory practices, we can better advocate for policy changes and interventions that promote inclusive and supportive work environments for PSMI, ultimately

breaking the cycle of occupational injustice they face (Laliberte Rudman et al., 2016). The empowerment gained through transformative PAR processes empowers co-researchers and stakeholders to actively contribute to removing social devaluation and create opportunities for individuals with mental illness to engage in meaningful, valued roles in the workforce (Wolfensberger, 2011).

5.5 Strengths and Limitations

Our participatory action research (PAR) project stands out for its commitment to establishing a sustainable partnership with individuals who have lived experiences of serious mental illness (PSMI). The formation of a peer-support network exemplifies the project's success, and this achievement can be attributed to two pivotal factors. Firstly, our adherence to PAR principles played a vital role, as we recognized and valued the unique perspectives and insights from lived experiences while embracing genuine power-sharing among all participants. Secondly, the diverse composition of our co-researchers contributed significantly to the project's effectiveness. Our co-researchers possess a wealth of knowledge and expertise in the fields of employment and peer-support group facilitation, bolstering the project's outcomes. Additionally, pre-existing familiarity among some co-researchers fostered a sense of cohesion within the group, leading to a strong commitment to the shared goal of combating workplace stigma and promoting inclusivity.

However, it is essential to consider the limitations of our research. One significant limitation is the homogeneity of our co-researchers, as they all fall within the middle-aged range (45 – 65 years), have substantial work experience, and have made considerable progress in their recovery journeys. While this shared demographic may have facilitated strong group cohesion and rapid recognition of pertinent job-related challenges and valuable insights, the contextual specificity inherent in the PAR approach may limit our ability to draw broad conclusions. Engaging individuals from diverse age groups, particularly young adults

at the outset of their recovery journey, in PAR could yield valuable and insightful outcomes into their unique employment-related challenges.

Even though authentic power sharing is a fundamental principle of participatory action research, it is important to acknowledge that this approach might not completely eliminate power dynamics. There could have been instances of unequal power relationships, for instance, between co-researchers with extensive knowledge and expertise in PSMI employment facilitation and those who had limited prior experience in this domain. As a result, the latter group may have deferred to the advice of the more experienced individuals when making decisions, which could have potentially impacted our research outcomes.

Moreover, I recognize that my position as a researcher in participatory action research deviates from the conventional, demanding continuous introspection and reflexivity throughout the research journey. My values, predispositions, and status as an international student navigating the nuances of mental health care and local employment support, my relative novelty to the PAR approach, and my interactions with participants could potentially have influenced both the research process and its eventual outcomes.

5.6 Future Directions, Implications for Further Research

Our participatory capacity-building project successfully culminated in establishing a sustainable peer-support group dedicated to creating resources and supporting PSMI at work. After the ten-week PAR sessions in December 2022, the co-researchers decided to reconvene in the new year. Since then, five co-researchers have consistently met every two weeks, demonstrating their commitment to the peer-support group. The research team continues to support the group by organizing these meetings and facilitating consistent communication with our co-researchers about the meetings, goals, and progress. We have described here the salient milestones that the group has achieved over the last six months in 2023.

The group collaboratively decided their name as HEAR US, abbreviating their mission: "**H**elping, **E**ducating, **A**dvocating, and **R**elating to others' needs. We are **U**nited to make a difference and provide **S**upport." They collaboratively decided on their Mission and vision statement, core values, and working guidelines that highlight established group norms and codes of conduct. Furthermore, they recognized the need for more core members and collaboratively drafted a call for expressions of interest. They are currently in the process of welcoming and integrating four new members into their team.

The group also resumed their work on evaluating their two-part digital story. They created and administered a survey and sent this educational resource to a small target audience comprised of trusted individuals with executive experience. The group collaboratively reflected on the feedback they gained and incorporated relevant changes to their educational resource. They plan to launch this on their website and their YouTube channel.

The group's plans for the near future include formalizing a governance structure to streamline their endeavors and developing resources for inclusive workplaces as content for their website. To sustain the group in the future, the co-researchers and the research team co-applied for a research grant, proposing further exploration of the effectiveness of a virtual peer-support network on job tenure in PSMI. A significant advantage of a virtual peer-support network is its broad reach, providing easy access to resources and support for PSMI in the future. The plan aligns perfectly with the goal of this research, which is to empower PSMI to sustain their jobs and thrive in inclusive workplaces.

A sustained partnership with this accessible peer-support network poses a valuable opportunity to develop a nuanced understanding of the influence of peer support on employment in PSMI. Furthermore, collaboration with like-minded organizations and presentations at various employment-related events present opportunities for our group to

share our findings with a broader audience. This will achieve our goal of increasing awareness and normalizing discussions about mental health and the lived experience of mental illness. Furthermore, dissemination of our research has the potential to grant us an audience with policymakers and give us opportunities to influence policy change regarding the employment rights and needs of PSMI.

The group's vision is to nurture the seed of a nationwide online peer support network. This ambitious initiative aims to expand the reach of our current peer-support group, enabling PSMI across the country to connect, share work experiences, and access valuable resources and support. By harnessing the power of technology, we envision a thriving virtual community that fosters a sense of belonging, empowerment, and resilience among PSMI.

5.7 Conclusions

In conclusion, this thesis project demonstrated the transformative power of engaging PSMI in the PAR process. Our focus on building a sustainable partnership with our co-researchers and our findings regarding a framework to conceptualize factors that influence job retention in PSMI are novel contributions to the field. Through the lens of the PEO model, we uncover the dynamic intersection between environmental, work-related, and personal factors shaping job acquisition and retention. These findings indicate a poignant need to combat mental illness stigma and promote inclusive workplaces for PSMI. Additionally, we draw attention to the power imbalance inherent in the workplace and create opportunities for employers to leverage their power to create psychologically safe work environments. This work sheds light on the complexities surrounding job retention for PSMI and offers a blueprint for peer support as an intervention. The potential impact of this thesis extends far beyond academia, as it strives to create changes and foster a sustainable social movement to challenge historical marginalization and improve the lives of PSMI in the workplace and beyond.

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APPENDIX A: University of Alberta Research Ethics Office Ethics Approval for This Study

Notification of Approval

Date:	September 9, 2022
Study ID:	Pro00123682
Principal Investigator:	Elizabethmary Thomas
Study Supervisor:	Shu-Ping Chen
Study Title:	Job retention and career development for people with serious mental illnesses: A Participatory Capacity Building project.
Approval Expiry Date:	September 8, 2023
Sponsor/Funding Agency:	SSHRC - Social Sciences and Humanities Research Council SSHRC

	Project ID	Title	Grant Status	Sponsor	Project Start Date	Project End Date	Purpose	Other Information
RSO-Managed Funding:	RES0049584	Job retention and career development for people with serious mental illnesses: A Participatory Capacity Building project	Awarded	Insight Development Grants	6/1/2020	5/31/2023	Grant	

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

Approved Documents:

Recruitment Materials

Updated poster ad for job tenure study phase 2

Letter of Initial Contact

Updated invitation letter

Consent Forms

Updated informed consent

https://arise.ualberta.ca/ARISE/sd/Doc/0/T2SDDEHGF08UR7L9AM9A4LIG0D/fromString.html   1/2

Questionnaires, Cover Letters, Surveys, Tests, Interview Scripts, etc.

Study design document: outline of each PAR session

Protocol/Research Proposal

Job retention and career development for people with serious mental illnesses: A Participatory Capacity Building project.

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the REB does not constitute authorization to initiate the conduct of this research. The Principal Investigator is responsible for ensuring required approvals from other involved organizations (e.g., Alberta Health Services, Covenant Health, community organizations, school boards) are obtained, before the research begins.

Sincerely,

Theresa Garvin, Ph.D, MUA, BA
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix B – Poster invitation to participate in the study

PARTICIPANTS NEEDED – RESEARCH STUDY
People experiencing mental illness

Staying on the job and advancing your career.

Researchers from the Faculty of Rehabilitation Medicine, University of Alberta, are exploring ways to develop a support network that improves job retention and career advancement in people experiencing serious mental illness.

Study title: Job retention and career development for people with serious mental illnesses: A Participatory Capacity Building project

If you identify as **a person experiencing mental illness and are currently employed or have been employed within the past twelve months**, we would like to invite you to participate in a series of in-person group discussions led by participants with the goal of improving job retention and career advancement. These discussions will be audio recorded, and your participation will remain anonymized as no personally identifiable information is captured. Your participation is voluntary, and results will be anonymized and confidential.

You will receive a $30 gift card for each of the 10 sessions that you attend. Refreshments and reimbursement of your travel expenses will be provided.

You are eligible to participate in this study if you meet the following criteria:

- You identify as a person experiencing mental illness.
- You are currently employed or have been employed in the last 12 months.
- You are able to commute to the venue of the study (Corbett Hall, University of Alberta).

If you have any questions about this study or would like to participate, please contact the PI of this project: Elizabeth Thomas, MSc candidate in Rehabilitation Science, Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, AB.
Email: elizabe4@ualberta.ca

Appendix C – Informed consent form for participants

Informed Consent Form

Title of Project

Job retention and career development for people with serious mental illnesses: A Participatory Capacity Building project.

Project Investigator:

Elizabeth Thomas, MSc candidate in Rehabilitation Sciences, Faculty of Rehabilitation Medicine, University of Alberta. Email: elizabe4@ualberta.ca

Supervisor:

Shu-Ping Chen, Associate Professor, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta. Email: shuping2@ualberta.ca; Tel: 780-492-3905

Details of the study

The purpose of this study is to develop a peer support network that focuses on improving job tenure and career advancement for people experiencing serious mental illness.

You are invited to participate in a Participatory Action Research study to co-develop a support network that focuses on ways to build your repertoire as valued employees and identify and manage challenges in achieving longer tenure and advancing in your careers. Your participation can help improve the career journey for people experiencing mental illnesses.

What's involved?

- You will be asked to attend ten group sessions, which will be held in-person once every week for two and a half months from October to December 2022.
- The sessions will take place at Corbett Hall, in Edmonton. The day and time for the sessions will be determined based on the availability of the participants.
- Each session will take about 2 hours.
- We will provide refreshments during the sessions and travel expenses to the venue will be reimbursed.
- There will be a facilitator who will ask questions and facilitate the discussions. You will be asked some questions relating to your opinions about your role as an employee and the influence of your workplace environment. Sample questions may include, "What does work mean to you? How would you describe your experience communicating with your manager and coworkers?" The process will include five steps: (1) problem identification; (2) outline appropriate actions; (3) collect relevant data; (4) analyze the data; and (5) reflect on the outcomes of the action(s) taken.

- You will receive a $30 gift card after attending each session as an appreciation and compensation for your time ($300 worth of gift cards in total for attending all 10 sessions). Participants who choose to withdraw from the study will still receive this compensation for each session that they participate in.
- The sessions will be audio-recorded, and the audio-recording will be transcribed to ensure accurate reporting of the information that you provide.
- The audio-recorded files will be encrypted and stored in a password-protected computer before and after being transcribed. The recordings and the transcripts will be stored for 5 years and then be destroyed.

Risks

We do not anticipate there being risk to you by taking part in this study. However, some might feel slight mental distress from questions that participants will be asked about their recalled experiences. To avoid such situations, it is up to you decide how much and what information you want to share. You can decide not to respond to any question that you are uncomfortable answering.

For those who feel distressed, here are some resources to call for help:

1. Alberta Health Services (AHS) Addiction and Mental Health
   https://www.albertahealthservices.ca/amh/amh.aspx
2. AHS helplines:
   Health Link – 811
   Addiction Helpline – 1-866-332-2322
   Mental Health Helpline – 1-877-303-2642.

Our research team will do our best to eliminate the risks related to Covid-19 that you might be exposed to. We will follow the public health orders from the Government of Alberta and requirements of the Chief Medical Officer of Health:

Safety protocol in amid of COVID-19 pandemic:

- We will maintain physical distancing as much as possible.
- Self-isolating when exhibiting symptoms of COVID-19. We will ask you if you have any symptoms of COVID-19 before the meeting. We will also ask you to self-isolate if you have symptoms after the meeting. The rule also applies to the researcher.
- We will have the meeting during non-peak hours.

We will provide masks and hand sanitizers during the meetings.
In addition, we do not have contact with the employers. Therefore, your participation in this research will not affect your job in any way.

Benefits

Participation in this study may benefit you in terms of developing a social support network focussed on finding ways to enhance your job tenure and career advancement. What we learn from these sessions will contribute to our understanding of the ways to support people with serious mental illness to sustain jobs and improve their career progression. Also, the participatory process will allow you to learn to identify and analyze issues related to employment, develop solutions and action plans to meet the need for support on and off work, and enhance your perceptions of personal empowerment regarding employment.

Confidentiality

Any information that you share is confidential. Your name will never appear in any of the study records. The study records will be kept in a locked storage space at the University of Alberta in the Faculty of Rehabilitation Medicine. Only the research team will have access to the study records. Any research reports that come from this study or other follow-up studies will not identify you in any way. The data collected in this research (such as themes derived from the sessions) might be used for other follow-up studies. The data will be maintained electronically for 5 years and then will be destroyed. Hard copies of the research data (such as the consent form) will be held for 5 years and then be destroyed.

It is important to keep confidentiality in the groups. We encourage you NOT to discuss anything mentioned in the groups outside of the groups. However, we are not able to guarantee your confidentiality in the groups.

Voluntary Participation

It is your decision to take part in this study. You can change your mind about participating in the study by contacting the Investigators or research assistant before attending any of the sessions. However, we are not able to remove what you said in the previous sessions.

Further Information:

Should you have any questions about this study, or are dissatisfied at any point with any aspect of this study, please do not hesitate to contact Elizabeth at the Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, AB. Phone number: (587) 937-7473. Email: elizabe4@ualberta.ca.

For questions regarding participant rights and ethical conduct of research, contact the University of Alberta Research Ethics Office at reoffice@ualberta.ca. This office has no direct involvement with this project.

Elizabeth Thomas,
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Faculty of Rehabilitation Medicine
University of Alberta

Edmonton, AB, T6G 2G4
587-937-7473   elizabe4@ualberta.ca

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Faculty of Rehabilitation Medicine
2-30 Corbett Hall, University of Alberta
Edmonton, AB, T6G 2G4
780-492-3905   shuping2@ualberta.ca

Consent and Some information about you, which help us get to know you better and will be maintained confidentially.

Name

Age

Gender identity

Currently working/ studying at ....   since....

Have previously worked/studied at.......

Preference for gift cards:

CONSENT

Title of Study: Using peer support to improve job tenure and career advancement in people with serious mental illness: A Participatory Capacity Building project.

Principal Investigator(s): Elizabethmary Thomas   **Phone Number(s):** 587-937-7473

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records?	☐	☐
Use of my research information beyond this study		
Do you agree for your information to be securely stored at the Faculty of Rehabilitation Medicine, University of Alberta to facilitate future reuse?	☐	☐

Who explained this study to you? _____

I agree to take part in this study:

Signature of Research Participant _____

(Printed Name) _____

Date: _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _____ Date _____

Appendix D – Letter of Invitation to Participate in our Study

Invitation Letter

Dear participant,

You are invited to participate in a study to help develop a peer support network that focusses on ways to improve people's job tenure and career advancement.

Title of Study: Job retention and career development for people with serious mental illnesses: A Participatory Capacity Building project.

You are in a unique position to contribute to this research because you have experienced mental health concerns and are employed or have been employed within the past 12 months. We would like to invite you to join in a series of group discussions (**10 sessions in total**) that will take place at Corbett Hall on the University of Alberta Campus in Edmonton.

In this research, we want to develop a peer support network for people who experience the same challenges. We would like to invite you to discuss, analyze, and reflect on the needs and challenges people faced as they endeavor to sustain their job and progress in their career. The discussions will help us gain a better understanding of the support you need. The support network will help people gain social contacts and support that may help in developing a role as a valued employee.

Each in-person group session will take about **1.5 to 2 hours** at the time and place convenient to you. We will provide **refreshments**, and you will receive a **$30 gift card** for each attendance. You will also be reimbursed for your travel expenses. The 10 sessions will be held **once every week for two and a half months** from October to December 2022.

Each session will be audio recorded, and your participation will remain anonymous as no personally identifiable information is captured. What we learn from the discussions will contribute to our understanding of the needs and ways to support people as they advance in their career journey. The research team has no contact with the employers. Therefore, your participation in this research will not affect your job in any way.

If you are interested in taking part in this study, please contact Elizabeth (elizabe4@ualberta.ca, facilitator for the group discussions), or Haley (hueitsz@ualberta.ca, research coordinator for the project) for details.

Principal Investigator
Elizabethmary Thomas, Master's student in Rehabilitation Sciences, Faculty of Rehabilitation Medicine, University of Alberta. Email: elizabe4@ualberta.ca;

Supervisor
Shu-Ping Chen, Associate Professor, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta. Email: shuping2@ualberta.ca; Tel: 780-492-3905

Appendix E – Notes from Session 2: Co-Researchers' List of Crucial Challenges in

Maintaining a Job

Crucial Challenges maintaining a job

Critical challenges in maintaining a job 10-18-22
- initial stress of the job can worsen
- apply for jobs under my skill level because I don't want too much stress
  I end up trying to solve all of the problems
- Finding myself in the wrong environment
- arthric complications
- not being myself & putting a mask on and not being able to maintain it
- too tired to be at the level of career I should be
- I don't have the money for my own place
- if I do not agree with delegation of labour I
- Employers not understanding anything about mental health issues
- treat me like a human (treating workers unfairly

- individuals may be more vulnerable with expressing mistreatment
- not having acceptance - not being able to talk about it
- not being able to fill your actual potential
- Stigma & how to reverse it
- How people presieve people with mental illness
- private sector has a bias
- ie construction companies
- By disclosing your mental health concern your openings up a potential avenue to let you go

- Bias- stigma, discrimination assumption that comes with a diagnosis (people live differently with different diagnosis)
- Western concept is ending, we are only as good as our social system
- "what goes on a mental illness look like?" (Society believes someone living with specific mental health diagnosis cannot do certain jobs)
- employees accomadating mH days \ appointments
- employees asking for mH day or time for appointments
- Employers recognizing when employee is in acute episode and needs to be sent

- fear of doing something different \ finding a good fit, staying in something familiar that is unhealthy
- Fear of feeling alone
- wanting to be treated like an equal, not treated "special" blc living is a mH concern.
- Concerned about miscommunication
- Forced into double shifts, missed time w family \ being taking advantage of, & allowing it for fear of upsetting employer.
- Trouble asking for modified work

- Precarious employment
- Lack of benefits or job security
- working in dangerous environments to pay the bills
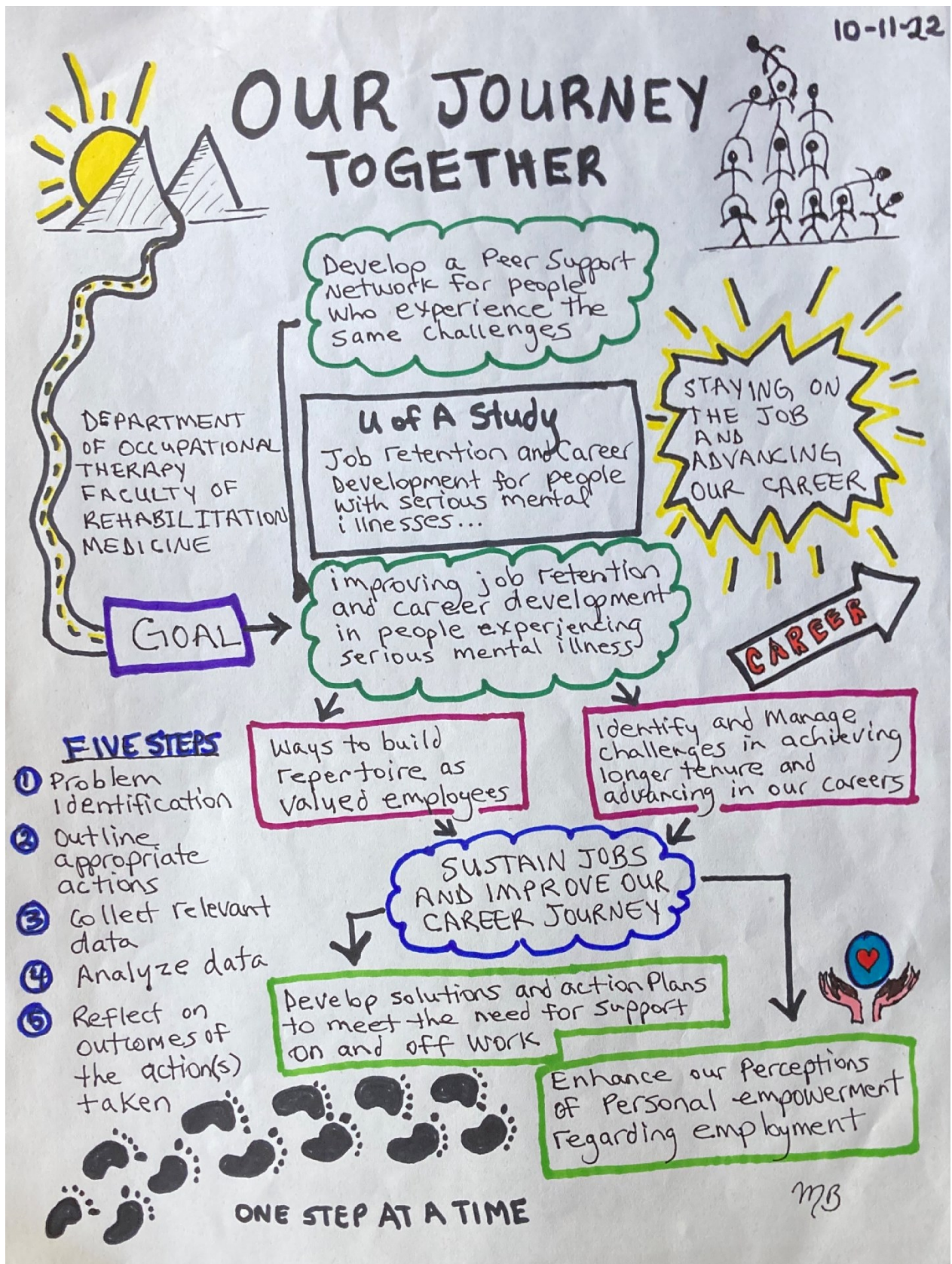
Appendix G – Notes from Session 5: "The Co-Researchers' Situation Target Plan"

Material taken from Mental Wellness Recovery Group - Founded by Sue Miller

CREATING THE LIFE THAT YOU WANT – PREPARING FOR ACTION PLANNING

Situation Target Plan Map (Session #8)

(This Goal-Setting method is called STP. Situation, Target, Plan. Often people will start planning how to get to a Goal (Target) before taking the time to outline their Situation)

1. In order to plan a trip, you first have to know where you are or you won't know which direction to go. So, when planning to get to your Target, it is best to start by first outlining your Situation. Then outline your "Target".
2. When you think about how to get to your Target or Goal, you can probably come up with many problems and things that will get in your way. We call these HURDLES. Things you have to overcome in order to get where you're going. Draw a line on your journey for each hurdle and then below the line describe each hurdle that stands in the way of getting from your current Situation to your desired Target State.
3. Of the hurdles identified, in order to achieve your ideal Target state which one would you like to make the most progress on in the next 30 days?
4. Rephrase this Hurdle so it is a goal rather than a problem.
5. You can then test the Hurdle/Goal, apply SMART goal rules and create an Action Plan to successfully complete this Goal (Covered in Session #9)

Target

How you'd like your life to be

We want people with Mental Health Illness to get jobs and to retain them

Hurdles

People with mental health conditions are usually very good at anticipating everything that can go wrong or get in your way. That happens to give you a real advantage in achieving your Target. Because the more problems you anticipate, the better your plan will be to get to your Target.

Go to the "Recovery Definition" you developed in Session #1. Is there something you underlined or added that would enhance your Target State above?

PEER WEBSITE
- a place to educate and provide resources

Create a group digital story
Create a hub for resources
Grants - success stories
Forms for employees and employers

EMPLOYEES - have trouble getting and retaining a job

Take training
- coping skills (self-care package (Formula for Staying Balanced and Wellness Card) - Ombudsmen - external advocate

Situation

What is your life like now? What aspects are unsatisfying or cause unhappiness for you?

People with Mental Health Illness struggle to find jobs and keep those jobs

Plan

EMPLOYERS - does not want to deal with challenges
- do not have a road map

Self-care package for employees (Formula for Staying Balanced and Wellness Card)
Collaborate with GEDI Hub and Embers - develop tools for employers
Mental Health Coaches
Employee assistance program
Recognize progressive employers

U of A Study - Job Retention and Career Development for people with serious mental illnesses

Name: _____ Date: November 8, 2022

Appendix H – Wellness Health Card by OUR Co-Researcher- M.B.

Formula for Staying Balanced	Name:	Date:

Mental Fitness	Medication	Nutrition
		Drink Lots of Water
Exercise/Activity	Breathe	Sleep
		Listen
	Finding Balance	Support Team
Work/Volunteer Balance		Self Advocate
		Set Boundaries
Enjoy Hobbies		Spiritual

Wellness Health Card	Name:	Date:
Warning Signs/Signs I'm Stressed	What I Can Do To Feel Better	What I Can Do With Others to Feel Better or How Others Can Support Me

Appendix I – Scoping Review of PAR in PSMI

Participatory Action Research in People with Serious Mental Illness: A Scoping Review

Participatory Action Research Among People With Serious Mental Illness:

A Scoping Review

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Abstract

Participatory Action Research (PAR) is a research approach that creates spaces for marginalized individuals and communities to be co-researchers to guide relevant social change. While working toward social transformation, all members of the PAR research team often experience personal transformation. Engaging people with serious mental illness (PSMI) in PAR helps them to develop skills and build relationships with stakeholders in their communities. It supports positive changes that persist after the completion of the formal research project. With the increasing recognition of PAR's value in PSMI, it is helpful to consider the challenges and advantages of this approach to research with this population. This review aimed at determining how PAR has been conducted with PSMI and at summarizing strategies used to empower PSMI as co-researchers by engaging them in research. This scoping review followed five steps Arkesy and O'Malley (2005) outlined. We charted, collated, and summarized relevant information from 87 studies that met the inclusion criteria. We identified five strategies to empower PSMI through PAR. These are to build capacity, balance power distribution, create collaborative environments, promote peer support and enhance their engagement as co-researchers. In conclusion, PAR is an efficient research approach to engage PSMI. Further, PSMI who engage in PAR may benefit from strategies for empowerment that meet their unique needs as co-researchers.

Keywords: Mental health, community-based participatory action research, psychosis, empowerment, patient-led research

Participatory Action Research among People With Serious Mental Illness: A Scoping Review

Participatory Action Research (PAR) is a research approach that embodies an emancipatory agenda and seeks to work with community members as co-researchers in building knowledge and guiding change (Rahman & Fals-Borda, 1991; Reason & Bradbury, 2005). The traditional separation of knowledge generation and action in research has been identified as problematic (Jacobs, 2018). However, PAR seeks to bridge this gap by integrating both into a single continuum (Benjamin-Thomas et al., 2018). PAR has three primary goals: generating practical, locally relevant knowledge, making knowledge accessible, and promoting individual and social transformation to meet the participants' needs (Schneider, 2012). What sets PAR apart from other research methods is its focus on equitable partnerships between researchers and communities, as well as its commitment to positive social change (Brydon-Miller et al., 2020; Wallerstein & Duran, 2008).

We can realize PAR's full potential by embodying its central tenets and principles. These include the sharing and negotiation of power, mutual respect, and maximizing PSMIs' equitable participation by helping them make informed decisions throughout the research process to guide relevant change (Benjamin-Thomas et al., 2018). According to Grant and colleagues (2008), managing resources, negotiating differences of opinion about the research process, and adapting to changes in the planned timeline can pose practical, philosophical, and interpersonal challenges in PAR. These challenges may arise due to participants falling ill, discontinuing participation, or requiring extra training and support. The level of co-researcher engagement and power negotiation between academic and community partners may vary at different stages within a research project depending upon such factors as level of interest, time available, experience, and resources available.

Understanding the value of PAR with PSMI, the challenges faced in carrying out PAR, and suggestions for practice from previous research (Desai et al., 2019; Schrank & Wallcraft et al., 2009) will help future researchers engage PSMI as co-researchers further. Several reviews have addressed the use of PAR with PSMI. Of two notable qualitative systematic reviews, one is on the experiences of young women with psychosis and their relationships (Chernomas et al., 2017). The other is about the complexities of sexuality and intimacy among PSMI (McCann et al., 2019). Further, there is an integrative review on consumer research to improve PSMIs' physical health outcomes (Happell & Roper, 2007) and a scoping review that explores the way that PAR can enhance young people's mental health and resilience (Raanaas et al., 2020). However, no reviewer has mapped the nature and extent of PAR with PSMI to date. The rationale for this scoping review was derived from the need to address transformation at both the community and individual levels in a better way. To this end, we compiled insights from published PAR studies on research priorities, methods and methodologies used, strategies to empower PSMI, and ways to involve them in PAR research.

The overarching goal of this review was to examine the documented use of participatory action research with PSMI. The specific objectives were to understand PSMIs' levels of engagement in the PAR process, trends in the research areas prioritized in PAR with PSMI, the various methods and methodologies used within PAR with PSMI, techniques to ensure methodological rigor, ways to facilitate personal and social changes, and strategies to enhance PSMIs' meaningful participation in various stages of PAR.

Methods

Study Design

A scoping review was considered an appropriate method, as it facilitates a bird's eye view of the research available on the extent and range of the research activity. We combined

the approach Arkesy and O'Malley (2005) described with recommendations by Levac and colleagues (2010). The review followed five steps: (a) identify the research question; (b) search for relevant studies; (c) select studies; (d) chart the data; and (e) collate, summarize, interpret, and report the results.

Step 1: Identification of the Research Question

The research question that guided the review is "What is known about the use of PAR with people with serious mental illness?" We define the term PAR with PSMI as "a research approach for enabling people diagnosed with mental health problems to take part in carrying out research and in doing so to promote health equity, citizenship, and social justice for people with a mental health diagnosis" (Schneider, 2012, p. 153). Community-Based PAR (CBPR) is a research approach in which researchers, community organizations, and community members, particularly people with lived experience of mental illness, engage in the research process collaboratively to effect social transformation (Sayer et al., 2019). This review uses PAR and CBPR synonymously to describe research that engages individuals and communities in collaborative knowledge generation and action. Serious Mental Illness (SMI) is a mental, behavioral, or emotional disorder that results in severe functional impairment and interferes with or substantially limits one or more major life activities (National Institute of Mental Health, 2023). Although SMI encompasses a variety of diagnoses, we use the term PSMI in this study to describe individuals with a diagnosis of schizophrenia, bipolar disorder, and any form of a psychotic disorder that severely marginalizes people living with SMI (National Collaborating Centre for Mental Health, 2014).

Step 2: Identification of Relevant Studies

Six electronic databases were searched in January 2022 using the relevant keywords and appropriate searching syntaxes. Of these, five major social science databases, including Medline, Embase, APA PsycINFO, CINAHL, and Scopus, were chosen to identify articles

from various disciplines. We included grey literature (ProQuest dissertations and theses) in our search to ensure a comprehensive overview of the research topic (Levac et al., 2010). The main concepts "Participatory Action Research" and "People with serious mental illness" were each cross-referenced using relevant keywords, including "participatory action research," "community-based participatory research," "Photovoice," for PAR, and "schizophrenia," "bipolar," and "psychotic disorder" for PSMI. No methodological or time limits were employed. We sorted the duplicates manually and scanned critical articles' reference lists to ensure a thorough search.

Step 3: Selection of Studies

Two independent researchers (ET and AS) screened the titles and abstracts, while ET screened the full text after that to identify studies that met the inclusion criteria. These criteria included studies published in English that used PAR or CBPR with PSMI and engaged them in the research process. During the full-text screening, we used the Critical Review Form – Qualitative Studies, v. 2.0 (Letts et al., 2007) to appraise articles concerning the criteria, including study design, descriptive clarity, and procedural rigor. We excluded articles that studied individuals with diagnoses other than those specified in our definition of PSMI.

The PRISMA flowchart (Figure 1) shows that the search yielded 1328 results. We identified and removed 525 duplicates and screened the remaining 803 titles and abstracts for their relevance to the inclusion criteria, and 560 studies were deemed irrelevant and excluded at this stage. Of the remaining 232 studies, we excluded 145 because they did not meet the inclusion criteria. This review included the remaining 87 studies, of which 10% (nine dissertations) were from grey literature.

(Insert Figure 1 here)

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Step 4: Charting of the Data

We used a descriptive-analytical method (Arksey & O'Malley, 2005) that applied a common analytical framework to the 87 studies included. We charted the general citation information, the study population's demographic characteristics, the study's purpose, methods used, key findings, the level of engagement, and strategies used to empower PSMI during the research process using the Covidence software (Covidence, 2022). Then, we exported the data as an Excel file for further analysis.

Step 5: Collation, Summarization, Interpretation, and Reporting of Results

We created a descriptive summary of the findings using a rudimentary descriptive analysis of the extent, nature, and distribution of the studies included. Directed content analysis, as Hsieh and Shannon (2005) described, was used to analyze and present the areas of research focus, the PSMIs' level of engagement in the research process, the specific strategies used for individual and social transformation with PSMI, the challenges faced during the research, as well as the measures used to ensure the trustworthiness of the studies included.

Results

General Description of the Studies Included

Demographic Information

Table 1 provides a complete list of the 87 studies included—the years of publication range from 1997 to 2021. Although a large proportion of the studies (70%) recruited participants who had been diagnosed with psychotic illnesses, 14 (16%) and 13 (14%) of the studies focused specifically on people who experience bipolar disorder and schizophrenia, respectively. Of the 87 studies, more than two-thirds (74.7%) were published in North America, 17% in Europe, and 3% in Australia. One study was international, and one study each was from Singapore (P55), China (P56), and India (P65).

Level of Co-researchers Engagement

Research has shown the value of developing partnerships with the community to facilitate PSMIs' meaningful participation (Rebeiro Gruhl, 2012). One of PAR's main principles is to involve participants as co-researchers actively within various phases of the research process (Baum et al., 2006; Hacker, 2013). The studies that used a CBPR approach reported the value of long-standing partnerships with community-based organizations, such as supportive housing agencies (P6) and local mental health agencies (P27), to create space for PSMI co-researchers to determine the research priorities, choice of methods, and use of the knowledge generated. This approach is exemplified in peer-directed research by the Collaborative research team that studies psychosocial issues in bipolar disorder (CREST BD). This Canadian research network focuses on applying CBPR in bipolar disorder research (P2, 18, 32, 75).

Similarly, 12 studies that described a PAR approach have engaged PSMI in all stages of the research process (P17, 23, 31, 40, 47, 50, 64, 66, 70, 71, 84, 85). PSMI co-researchers were part of an advisory group with relevant stakeholders, which allowed them to guide the research priorities and the methods used and take ownership of the knowledge generated. Examples of advisory groups include a steering committee (P16) to improve workplace mental health and a "PAR co-design team" to explore recovery from psychosis and resilience (P34).

The articles exhibited variations in how PSMI set research priorities, determined data generation methods, and disseminated the findings. Eight studies (P28, 33, 40, 41, 50, 61, 63, 66) elaborated on the role that PSMI play in determining the research priorities (e.g., facilitators and barriers to living with psychosis by a group of students with lived experience, P50). Six studies described the way PSMI co-researchers engaged in generating knowledge by conducting in-depth interviews (P74), focus group discussions (P31), developing

workshops (P34), and videos that describe ways to reduce mental health stigma (P66). Eight authors reported engaging co-researchers in data analysis through methods such as consumer concept mapping (P26), developing narratives for their photographs in a Photovoice study (P73), and engaging in group discussions (P37, 50, 64, 70, 74, 84).

Participant-led ways of sharing the knowledge acquired included community forums (P14), a group theatre presentation (P31), a meet the authors' event (P36), community displays of artwork (P80), screening videos to reduce mental health stigma (P66), and distribution of a list of strategies to improve housing facilities to policymakers (P47). In most Photovoice studies, co-researchers hosted a public display of their photos to encourage conversations about their perspectives (e.g., P1, 55, 84). Other methods of sharing knowledge reported include peer-led websites (P9) and including peers as co-authors in publications (e.g., P31, 71, 87). Several papers referred to study participants as "service user researchers" and "participant co-researchers" (e.g., P6, 71, 82).

Research Areas Prioritized in the Studies

The studies in this review prioritized three main research areas: activity and participation, environmental aspects, and PSMIs' overall conception of recovery (see Table 1 and Figure 2). We used the ICF (World Health Organization, 2001) as a guiding framework to identify critical sub-categories. We found that 29 of the 87 articles (33%) focused on activity and participation and included such topics as self-care, interpersonal interactions, and responsibilities, such as fulfilling the role of parenting (P24), access to, and engagement in, significant life areas like employment (P17), and social participation. As shown in Table 1, 12 studies explored participant-oriented interventions to promote self-care, such as increased physical activity (P3), healthy food choices (P10), and digital self-management strategies (P2).

Approximately half of the studies included (n=41, 47%) explored environmental

aspects that affected PSMI, including topics such as the presence of stigma (P33), challenges

in supportive housing (P58), and client-led evaluation of mental health services (P38). For

example, 24 studies reported topics related to clients' understanding of schizophrenia's

causes and consequences (P40) and developed a questionnaire to assess the quality of mental

healthcare (P41). The participants' conception of recovery was the focus of 20% (n=17) of

the studies. It included topics such as the personal meaning of recovery (P75), the effect of

the participatory clubhouse model on the recovery process (P73), and the development of

resilience (P86).

<center>(Insert Figure 2 and Table 1 here)</center>

Methods Used in the Studies

PAR allows for flexibility concerning methods and methodologies used to generate

and disseminate data. The studies included in this review reported using a PAR or CBPR

approach with various qualitative and mixed method designs that suited their research

question. Most (n=68, 78%) used qualitative methods, among which 45 studies (52%) used

focus group discussions (FGDs) and 21 (24%) used the Photovoice methodology. Other

qualitative methods used included in-depth interviews (e.g., P1, 21, 68), group discussions

(P5), concept mapping (P26), and participatory video (P66). A mixed methods design was

employed by 19 (22%) studies, with such quantitative methods as pre- and post-intervention

surveys (e.g., P29, 38, 78) and cluster analysis (P46) in conjunction with qualitative methods

such as FGDs.

Methodological Rigor of the Studies Included

Methodological rigor is essential in qualitative research and applies to participatory

research methods (Tracy, 2010). Most of the studies reviewed reported using methods that

Lincoln and Guba (1985), Yardley (2017), and Padgett (2016) recommended to ensure

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trustworthiness throughout the research process. In this review, 34 authors (39%) utilized member checking to verify that their preliminary findings accurately reflected the collective experience of their co-researchers (e.g., P6, 31, 65). Additionally, 17 (19.5%) authors described triangulation (e.g., P11, 49, 56) and combined methods such as in-depth interviews and focus group discussions with Photovoice to develop a more comprehensive understanding of their findings. Six (6.9%) studies reported engaging PSMI in data analysis (P6, 10, 31, 57, 64, 86) to ensure credibility. For example, a study of healthy living among PSMI enlisted interested co-researchers to read anonymized transcripts of focus group discussions to identify preliminary themes (Weinstein et al., 2019). A majority (81, 93%) of the studies used purposeful sampling, and 25 (28.7%) provided detailed descriptions of the co-researchers and research site, including verbatim quotes by co-researchers to ensure a detailed description of the context, and allowed the reader to determine the way that the findings applied to their contexts (e.g., P13, 22, 65). However, very few studies provided reflexive notes on the researchers' positionality, theoretical perspectives, and biases or the challenges faced within the research process (e.g., P31, 64, 82).

Individual and Social Change

Collaborative action to effect positive change is a crucial tenet of PAR (Benjamin-Thomas et al., 2018). The research process and its outcomes foster such change on multiple levels, including personal, local, regional, and national (Brydon-Miller et al., 2020). PSMI gained new skills, including research skills, coping strategies for stigma (P33), new knowledge concerning self-management techniques and healthy food options (e.g., P3, 25, 50), increased self-awareness (P59), and reduced self-stigma (P66). They described empowerment as having a seat at the table (P34), being listened to (P48), and being able to use their voice to influence policy change (P58).

Social change was evident in the increased local awareness of PSMIs' concerns, such as difficulty in accessing healthy food options (P1), lived experience of homelessness (P59), and challenges in supportive housing (P47), which led to a deeper understanding of mental illness stigma's effect (P33, 50, 60). One study on college students with mental illness resulted in a campus-wide campaign to encourage discussion about mental health (P20). Collaboration with community-based organizations and peer-led groups in the research process facilitated the development of supportive social networks, such as a community garden (P21) and physical activity groups (P3), some of which continued after the formal research process (e.g., P4, 28, 61). The action taken by research groups influenced policy change concerning employment opportunities (P13) and supportive housing facilities (P58).

Strategies to Empower PSMI Through Engagement in PAR

Sundar and Ochocka (2009) described empowerment as an opportunity for people to gain control to influence recommendations and actions needed to realize individual and social transformation. An essential goal of participatory research is to empower co-researchers to become aware of and develop agency to, advocate for their own needs and those of their community (Brydon-Miller et al., 2020). We adapted Chen and Krupa's (2018) framework of empowerment to categorize five critical strategies used in the studies reviewed to engage and empower PSMI through PAR. These are to build capacity, balance power distribution, create a collaborative environment, promote peer support, and enhance engagement in the research process (See Figure 3).

(Insert Figure 3 here)

Building Capacity

Engaging PSMI in research requires valuing their lived experience and creating opportunities to acquire new knowledge and skills that are meaningful to them and relevant to the research process. For example, a peer-led study (P2) developed a web-based resource

called "The Living Library," where PSMI could share experiences with a peer expert who could understand and relate to them. In a study designed to enhance PSMI youth's awareness of self-management strategies (P4), the author highlighted the importance of allowing participants longer timelines to build capacity and confidence as they gradually assumed new responsibilities. Engagement in research also facilitated the development of research skills, such as interviewing (e.g., P3, 11, 72), research ethics (P4), data collection and analysis methods (e.g., P17, 38, 48), as well as transferable skills, such as leadership (e.g., P20, 46, 82) and group facilitation (e.g., P11, 31, 63). These skills equipped PSMI co-researchers to think critically, recognize their role, take responsibility, and make informed decisions in various stages of the research process.

Balancing the Distribution of Power

The equitable distribution of power is one of PAR's critical principles. Because previous negative research experiences took PSMI for subjects and treated researchers as experts, the research team is inherently in a powerful position compared to PSMI co-researchers (P31). Some researchers recognized the need to shift the power distribution in favor of PSMI co-researchers intentionally and used strategies such as ensuring adequate representation of PSMI co-researchers in the research team (P7, 9, 26), valuing them as experts according to expertise (P34), acting on their recommendations (e.g., P26, 37, 72) and providing opportunities for them to build capacity, assume responsibilities, and guide decisions throughout the research process (e.g., P38, 51, 62). Transparency concerning the research process (P64) and an informal environment (e.g., P28, 31, 37) helped the co-researchers share their opinions from a position of agency. Hiring PSMI as paid co-researchers (P49) and encouraging them to take ownership of their work and co-author publications (P34, 71, 87) was also reported to promote equitable power distribution.

Creating a Collaborative Environment

A collaborative environment is one in which all participants are valued and can contribute to various aspects of the research process. Researchers recognized the importance of creating an affirming environment to enable PSMI co-researchers to negotiate and share power from a position of agency (P72). Studies that invested adequate time to develop long-standing partnerships with community and peer-led groups reported that familiarity with the research team and trust built over time enhanced the engagement of PSMI co-researchers in the research process (e.g., P4, 31, 82). Strategies used to create a collaborative atmosphere included encouraging and modeling the use of strength-based language (e.g., P6, 20, 31), inviting them to express their ideas and feelings (P64), and promoting understanding, solidarity, and socially responsible ways of relating to each other (P23). For example, in a study that explored recovery from and resilience in psychosis, the PAR Co-Design Team, including PSMI co-researchers, engaged in collaborative discussions about addressing their concerns proactively concerning ethical issues and decisions about self-identifying as people with lived experience (P34).

Peer Support

Many studies have reported that sharing personal challenges in a safe space promoted a feeling of normalization of individual experiences (P8, 21, 55) and led to a sense of belonging through mutual support and affirmation (P28). In a Photovoice study on the effect of engaging in a clubhouse, PSMI described that the confidence built in Clubhouse activities helped them feel more able to pursue opportunities outside the Clubhouse (P28). Further, collaboration to achieve a common goal fostered a connection among those involved (P4). For instance, in a community gardening project, the author reported that PSMI co-researchers assumed and fulfilled roles voluntarily, which contributed to an atmosphere of belonging and

strengthened their sense of purpose and place within the group further through validation from others (P21).

Enhancing Meaningful Participation

PSMI participants require support to meaningfully engage with the research process and experience individual and social transformation. The studies reviewed showed three critical strategies used to bolster their participation: (a) address barriers to participation; (b) clear and consistent communication; and (c) provision of support throughout the research process.

Addressing Barriers to Participation. Research has established that PSMI can contribute meaningfully and play leadership roles in the PAR process. To better support their engagement in PAR, it is crucial to understand and address neuro-cognitive, emotional, and practical barriers to participation that some PSMI may face. Because of their diagnosis, some may have neurocognitive difficulty concentrating, remembering information, and articulating their thoughts (P31). To overcome these challenges, researchers have used strategies to enhance engagement, such as visual aids (P42), printed information sheets (P19), reminder emails about upcoming meetings (P4), and created a safe space for PSMI to articulate and express their thoughts at their own pace (P31, 25, 42).

Other articles described how PSMI coped with emotional challenges such as self-stigma and fears concerning the nature of their involvement in research (P23, 31, 42). To address these barriers, researchers reported the benefits of prolonged engagement with the research team in developing trust and enhanced co-researcher engagement over time (P31). Side effects of psychotropic medications, such as fatigue and altered sleep patterns, may affect PSMIs' participation as well. Researchers have addressed this by planning research activities with PSMI collaboratively at a suitable time, reducing participants' burden by giving them control over the nature of their engagement (P68) and creating opportunities for

them to surmount these barriers and contribute significantly to various stages in the PAR process (P23, 40, 42).

PSMI co-researchers experienced marginalization and reported challenges, including difficulty finding employment, homelessness, and being more vulnerable to comorbidities (P52). Most of the studies included reported that they provided the PSMI co-researchers with incentives, such as gift cards (P13), healthy refreshments (P29, 50, 76), and reimbursement for transportation expenses (P44), to overcome these practical barriers and encourage continued participation. For example, a study designed to improve PSMIs' access to primary care hired people with lived experience as paid co-researchers to promote equitable participation (P49). As described in the strategies above, researchers have tailored their approach to supporting PSMI to overcome barriers to participation in PAR.

Clear and Consistent Communication. Many researchers reported the effectiveness of using clear language and communicating with PSMI co-researchers regularly throughout the research process (P4, 39, 69). Young adult co-researchers appreciated setting timelines collaboratively, which allowed them to balance education and work commitments with research commitments (P22). Older co-researchers in a Photovoice study appreciated written instructions and weekly calls to remind them of the theme and the instructions before the next meeting (P61). Communication about the research goals, outcomes, roles, and anticipated challenges in the research process helped co-researchers gain clarity and feel confident in participating in the research project (P42). Further, PSMI co-researchers valued opportunities to express their additional thoughts, feelings, and ideas at the end of the research project (P19, 65, 82).

Providing Support Throughout the Research Process. It was imperative to intentionally provide PSMI co-researchers with ongoing support to empower them to engage fully in the research process. This support ensured that professional resources were available

to help them cope with the discomfort that may arise during the group discussions (P20, 61). To help service-user participants feel supported and to help them retain a sense of control concerning the information they chose to share, their consent was sought before each step of the study (P4). They also had the option of bringing along a carer or having a quiet place to retreat (P13, 62). Particularly during interviews that discussed sensitive issues with the participants, researchers found it useful to intentionally spend time with participants throughout the research, and they also made follow-up calls to offer support and help participants whenever necessary (P85).

Discussion

This scoping review provided an overview of how PSMI engaged in PAR processes. Our findings included demographic information identifying the country where the research was conducted, diagnosis of PSMI co-researchers, research priorities, methods and methodologies used, and their experiences of individual and social transformation through participation in PAR. We categorized specific strategies used to empower PSMI co-researchers, including building capacity, balancing power distribution, creating a collaborative environment, promoting peer support, and enhancing meaningful participation in the research process.

Equitable participation and social transformation are central tenets of PAR (Benjamin-Thomas et al., 2018). Many articles in this review described how they encouraged the participation of PSMI co-researchers in various phases of research. However, there was significant variation in the extent of involvement of co-researchers among the studies. Some described the engagement of co-researchers as *full participation* right from the design of the study to the dissemination of information (e.g., Paton et al., 2018; Schneider et al., 2004; Whitley et al., 2020), while others used the same terms to describe engagement in generating knowledge, without participating in setting research priorities or enacting social

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transformation through the research process (e.g., Morgan et al., 2003; Sameby et al., 2008; Skoy & Werremeyer, 2019). Similar inconsistencies regarding how principles of *participation* and *action* are enacted within PAR have been discussed and problematized in a critical interpretative synthesis of PAR with older adults (Benjamin-Thomas et al., 2018).

PAR is particularly relevant for PSMI, as they have been traditionally excluded from influencing clinical and research decisions concerning them. The prevalent description of PSMI as *patients* or *passive objects of study* causes them to feel uncomfortable in their roles and widens the gap between them and the research team (Rempfer & Knott, 2022). To achieve PAR's emancipatory agenda, it is crucial to bridge this gap by creating opportunities for PSMI to acquire knowledge and build the capacity to shape research priorities from a position of agency (Lapadat et al., 2020).

Within the scope of this review, the researchers organized workshops to train interested co-researchers in relevant research methods and methodologies (e.g., Russinova et al., 2018; Terp et al., 2016; Thai et al., 2021). Further, it was common for the research team members who were open to further changes on the part of PSMI co-researchers during the PAR process to set the initial research priorities (e.g., Sims-Gould et al., 2017; Weinstein et al., 2019). Benjamin-Thomas and colleagues (2018) also observed a similar trend in their critical interpretative synthesis of PAR with older adults as co-researchers. They described the importance of researchers' pre-establishing broad, open-ended research priorities and allowing co-researchers to shape the research process. Most of the studies included long-standing partnerships with community-based organizations or with peer-led groups that catered to PSMIs' needs and facilitated the process (Quintas & Burnett, 2013; Stanhope & Henwood, 2014; Stone et al., 2018). Our findings were consistent with existing research that found that such prolonged engagement helps build trust on the PSMI participants' part and

creates space for them to shape the research priorities and methods and take ownership of the knowledge generated (Moro et al., 2022).

Reflexive accounts of research processes are significant in all forms of qualitative research. In Tracy's (2010) eight "Big Tent" criteria for qualitative research, she emphasized the importance of practicing "honesty and transparency about the researcher's biases, goals, and foibles as well as about how these played a role in the methods, joys, and mistakes of the research" (p. 841). Engaging in reflexivity is particularly important within PAR, as the researchers must address sharing and negotiating power continually and reflexively throughout the research process to "explore, navigate, challenge, and share the process of attempting to break traditional power differences between researcher and participants" (Benjamin-Thomas et al., 2018, pp. 10-11). All of the studies reviewed recounted information about the researchers' professional background, the roles of those involved, and their rationale for various decisions in the research process. Several authors went beyond the basic introductory statements to offer reflexive and nuanced accounts highlighting their position as researchers, their biases, their challenges, and the rewards of carrying out PAR with PSMI.

Strategies that some authors in the studies reviewed used to describe their positionality included disclosure of their ethnicity (Du Bois et al., 2020), identity as a psychiatrist who is a mental health service user (Tischler et al., 2010), and the way that this positionality as an insider influenced their engagement, and that of their co-researchers within the research process. Some authors used "I/We statements" to describe their reflexive experiences during the research process. For example, one service-user researcher shared, "At times, I had difficulty allowing the co-researchers time and space to explore what they were being asked to do … and the need at times to be pragmatic" (Robertson et al., 2020, p. 489). Novice researchers who seek to use PAR would benefit from such transparent accounts of self-reflexivity and disclosure about how seasoned researchers facilitated co-researcher

engagement, coped with the challenges and unexpected difficulties they faced, and how research priorities evolved (Tracy, 2010).

While acknowledging the value of the researcher's positionality in enhancing PSMIs' engagement in research, it is essential to note that disclosing the authors' identities, particularly that of consumer researchers, is a delicate topic that merits careful consideration. In an article on the benefits and disadvantages of self-identification in social research, Massoud (2022) discussed how self-identification may affect researchers who belong to marginalized communities disproportionally by opening themselves and their work to devaluation. It might make researchers hesitant to disclose positionality statements. Massoud further recommended that all social researchers acknowledge their privileges and vulnerabilities regularly, as it may render positionality an integral part of social research. A judicious description of how authors shared and negotiated power differences and achieved meaningful engagement with PSMI co-researchers would help strengthen the quality of PAR with this population.

PAR calls for collaborative action to address contextual forces that shape injustices at the individual and collective levels (Benjamin-Thomas et al., 2018). It can range from raising the affected community members' awareness of a shared concern to influencing changes in local, regional, and national practices and policies (Brydon-Miller et al., 2020). This range is evident in how studies in this review achieved *action* and *transformation*. While most described the effect of collaborative action with PSMI, 11 studies addressed the way that they achieved *transformation* through the PAR process explicitly (Barrow et al., 2014; Guy et al., 2020; Maniam et al., 2016; Robertson et al., 2020; Sayer et al., 2019; Schneider et al., 2004; Stanhope & Henwood, 2014; Sundar & Ochocka, 2004; Toney et al., 2018; Weinstein, 2018; Yung, 2018). For example, in a PAR project designed to enhance communication between clinicians and PSMI, Schneider and colleagues (2004) described social transformation and

stated that PAR "empowered one small group of very marginalized people with schizophrenia to speak directly to psychiatrists and other mental health professionals about their treatment experiences and through this is contributing to change in how others with mental illnesses are treated by their healthcare professionals" (p. 576).

In future accounts of PAR, explicit descriptions of how PSMI achieved transformation in various contexts can promote its further use with this marginalized population. In addition, the need to report strategies transparently to minimize risks and protect participants, communicate clearly about data ownership, and explore ways to educate ethical review boards to ensure that research models are consistent with PAR's principles must be addressed continually in scholarship (Campbell-Page & Shaw-Ridley, 2013). Further, PAR researchers need to advocate for increasing research that explores and addresses the effect of social determinants of health, particularly on marginalized communities, such as PSMI, and their priorities for change. Graduate students would benefit from specialized training in PAR's use and application to a broad range of populations and diverse contexts, including research for policy change. Such efforts can create more space and opportunities for funding and training in participatory and transformative research approaches that address marginalized communities' needs.

We also discussed five strategies in the articles reviewed to empower PSMI by engaging in PAR. These included building capacity, balancing power distribution, creating a collaborative environment, promoting peer support, and increasing engagement in the research process (Chen & Krupa, 2018). These strategies are consistent with the basic principles in the PAR literature to build the capacity of co-researchers and share power with them to address their experiences of injustice. Understanding barriers that prevent participation, using techniques to support participation, communicating clearly and consistently, and providing incentives and support are ways to enhance PSMI engagement in

the research process. These are consistent with good practice guidelines for service user engagement, as Wallcraft and colleagues (2009) described. They stressed the need to involve PSMI from the outset of the project so that they have maximum influence and involvement. PAR researchers have cautioned that "inadequate time for involvement by peer researchers can render their participation superficial" (Lapadat et al., 2020, p. 7) and recommended that researchers include time for flexibility and delays in the research process (Lincoln et al., 2015).

Limitations and Conclusion

The implications of our findings need to be seen in light of certain limitations. First, this review summarized and discussed information in the articles but did not include details (e.g., the extent of power-sharing between academic and community partners) because of space constraints. As our eligibility criteria included research published in English, we may have excluded other relevant literature. Lastly, within the premise of a scoping review, we limited our efforts to collate, summarize, and report results. We did not delve deeper into a critical analysis of the articles included.

In conclusion, this study contributed to the PAR literature by summarizing the nature and scope of PAR with PSMI. It highlighted five broad strategies to empower them, ways to enhance their meaningful participation in the research process, and recommendations to accommodate their needs better. Building on the work of Wallcraft and colleagues (2009), we recommend nurturing relationships among participants, building their capacity to make decisions concerning the research and action processes, finding ways to increase access to resources, accommodating their unique needs, and addressing barriers to participation. Finally, the PAR literature would benefit from reflexive accounts of the research process, reviews that explore changes attributable to PAR, and its utility in addressing specific

research-related concerns, such as ethical considerations unique to engaging PSMI co-

researchers and particular ways to accommodate their needs better in the research process.

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