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Elham Javadizadeh

Abram Oudshoorn

Lori Letts

Skye Barbic

Chelsea Shanoff

*See next page for additional authors*

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## Authors

Elham Javadizadeh, Abram Oudshoorn, Lori Letts, Skye Barbic, Chelsea Shanoff, and Carrie Anne Marshall

# Participatory Research with Persons who Experience Mental Illness in Occupational Therapy: A Scoping Review

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La recherche participative avec des personnes souffrant de troubles mentaux en ergothérapie: un examen de la portée

Elham Javadizadeh , Abram Oudshoorn, Lori Letts, Skye Barbic ,  
Chelsea Shanoff, and Carrie Anne Marshall 

**Key words:** Mental health; Mental health services; Community-based participatory research; Participatory action research; Occupational therapy.

**Mots clés :** Santé mentale ; Services de santé mentale ; Recherche participative en milieu communautaire ; Recherche-action participative (RAP) ; Ergothérapie.

## Abstract

**Background.** Persons who experience mental illness also face stigma and discrimination that frequently lead to a loss of ability to exercise autonomy and agency in their lives. **Purpose.** The range and breadth of literature exploring participatory research with persons living with mental illness are unknown in occupational therapy and occupation science. We initiated this study to fill this gap in the existing occupational therapy and occupational science literature. **Method.** Using the method of Arksey and O'Malley, we have conducted a scoping review to identify the range and breadth of literature. A qualitative content analysis was performed. **Findings.** A total of 34 articles were included in the narrative synthesis. The content analysis led to three related themes from the included studies: (1) *coming together*; (2) *unique potential of participatory research*; and (3) *challenges in conducting participatory research*. **Conclusions.** This review highlights that participatory research is well suited to research conducted with persons living with mental illness to support meaningful engagement and minimize stigma throughout the research process. This review can guide future participatory research and practice in occupational therapy and occupational science with persons living with mental illness.

## Abstrait

**Contexte.** Les personnes souffrant de troubles mentaux font également face à la stigmatisation et à la discrimination, ce qui entraîne souvent une perte de leur capacité à exercer leur autonomie et leur agence dans leur vie. **Objectif.** L'étendue et la portée des recherches explorant la recherche participative avec les personnes vivant avec des troubles mentaux restent inconnues dans le domaine de l'ergothérapie et des sciences de l'occupation. Nous avons lancé cette étude afin de combler cette lacune dans la littérature existante en ergothérapie et en sciences de l'occupation. **Méthode.** En utilisant la méthode d'Arksey et O'Malley (2005), nous avons réalisé un examen de la portée pour identifier l'étendue et la portée de la littérature. Une analyse de contenu qualitative a été réalisée. **Résultats.** Un total de 34 articles ont été inclus dans la synthèse narrative. L'analyse de contenu a révélé trois thèmes liés issus des études incluses: (1) Se rassembler; (2) Le potentiel unique de la recherche participative; et (3) Les défis de la réalisation de la recherche participative. **Conclusions.** Cette revue met en évidence que la recherche participative est particulièrement adaptée à la recherche menée auprès des personnes vivant avec des troubles mentaux, afin de favoriser leur engagement significatif et de réduire la stigmatisation tout au long du processus de recherche. Cette revue peut servir de guide pour orienter les futures recherches participatives et les pratiques en ergothérapie et en sciences de l'occupation avec les personnes vivant avec des troubles mentaux.

## Introduction

Participatory research is a broad concept encompassing a wide variety of approaches to empower community members to participate in research and thereby engage them in making decisions that influence their lives (Jason et al., 2004). According to Balcazar et al. (2006), a participatory approach includes recognition of persons with lived and living experiences as research collaborators and engages them as active participants in all research phases, including defining the problem to be addressed, data collection, interpretation, and dissemination of findings. One of the significant differences between participatory approaches and other research models is that community members are involved in shaping research questions, and the traditional roles reserved for researchers, consumers, and service providers are reconceptualized (Balcazar et al., 1998).

Participatory research is an umbrella term for a range of approaches that incorporate individuals with lived experiences, service providers, and stakeholders throughout the research process (Cargo & Mercer, 2008). Green et al. (1995, p. 5) defined participatory research as “systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change.” While participatory action research is the most familiar term to most researchers (MacDonald, 2012), additional parallel approaches include community-based participatory research (CBPR), action research, and experience-based co-design (EBCD), among others. The purpose of action research is to improve the capacity and practice of the researcher instead of producing theoretical knowledge and does not always engage research participants in the study (Elliot, 1991). In participatory research and CBPR, researchers and community co-researchers collaborate to change a social reality (Whyte, 1998). Participatory action research is the combination of action research and participatory research with the goal of improving the capacity and practice of researchers and changing social reality through participation (Elliot, 1991).

Letts (2003) indicates that two key concepts of occupational therapy have a strong link with participatory research principles: client-centred practice and occupation. Participatory research, like client-centred occupational therapy, emphasizes bringing participants to the process of research and using their expertise to develop knowledge. In both participatory research and client-centred occupational therapy, the knowledge that participants bring to the encounter is crucial (Letts, 2003). The core values of client-centredness, such as the right of a person to choose occupations, are congruent with the holistic view of occupational therapy and the theoretical framework of occupational performance (Law et al., 1995).

A second connection between participatory research and occupational therapy is the concept of occupation (Letts, 2003). Occupation has a significant role in promoting health (Egan, 2022). Participatory research can be thought of as an occupation in itself in that the concept of “action” is considered a key component of the research process (Letts, 2003). In occupational therapy and occupational science literature,

participatory approaches have been conducted with persons with different health conditions, including persons living with physical disabilities (Bhagwanjee & Stewart, 1999), adults with mental health conditions (Andonian, 2010), older adults (Andonian & MacRae, 2011), occupational therapists (Egan et al., 2004), children with mental health disorder (Greco et al., 2017), immigrants and refugees (Suarez-Balcazar et al., 2018), and low-income communities and individuals with chronic health conditions (Wang, 1999).

## The Relevance of Participatory Research for Persons Living with Mental Illness

The unique strengths and challenges faced by diverse persons who experience mental illness present an important opportunity for using participatory approaches that take an occupational perspective. Mental illness refers to a wide range of conditions that affect cognition, emotion, and behaviour that can create challenges for occupational participation (Manderscheid et al., 2010). The importance of involving diverse individuals with mental illness in the development of approaches that are co-designed has been broadly recognized as an ideal approach in refining and creating innovative health systems (Chodo, 2015). According to Bassman (2001), persons living with mental illness have historically lacked a voice, and they are infrequently involved in decision-making about the mental health services. The historical oppression faced by persons living with mental illness makes this population a key group with which to conduct participatory research, as listening to and acting upon their perspectives is an opportunity to reconcile past oppression (Kleintjes, 2012).

## The Current Study

Participatory approaches have been used in a variety of ways within occupational therapy and occupational science; however, little is known about the scope of participatory research conducted with persons living with mental illness specifically. Understanding the breadth of literature in this area will provide a foundation on which to advance research and knowledge in action. Although there are number of reviews on participatory research and health in other disciplines (Stacciarini et al., 2011) or with other populations (Rustage et al., 2021), to our knowledge, there are no existing systematic or scoping reviews which have been conducted to synthesize literature on participatory research with persons living with mental illness in occupational therapy and occupation science. To fill this gap in the existing literature, we conducted a scoping review guided by the research question: *What is the scope of participatory research within the field of occupational therapy and occupational science regarding persons who experience mental illness?*

## Method

We conducted a scoping review following the methodological framework outlined by Arksey and O'Malley (2005) using the PRISMA-ScR guidelines (Tricco et al., 2018). Arksey and

O'Malley's framework encompasses five steps, which are described below.

### Search Strategy

We initially deployed our search in November 2021 and updated our search in December 2022. Our search combined the concepts of participatory research (e.g., participatory action research, photovoice) and occupational therapy and occupational science (occupational therapy\*, occupational science) using a Boolean "AND." The search strategy was deployed in nine databases (Medline, Embase, CINAHL, Sociological Abstracts, Nursing and Allied Health, Social Service Abstracts, Social Work Abstracts, Cochrane and PsychoINFO). A sample of our search, deployed in Medline, is provided in Appendix 1.

**Inclusion and Exclusion Criteria.** We included articles that: (a) used participatory research approaches; (b) pertained to persons who experience mental illness or mental health challenges; (c) were published in English or Persian; (d) published in all years; (e) pertaining to persons of all ages; (f) scoping and systematic reviews of empirical studies; and (g) had been published within the field of occupational therapy or occupational science (e.g., it was published in an occupational science or occupational therapy journal or was written by a first or last author identifying as an occupational therapist or occupational scientist).

We excluded articles under the following criteria: (a) action research studies that were not explicitly participatory; (b) conference abstracts; and (c) dissertations and theses.

**Study Selection.** We uploaded our searches from each database into Covidence™ (*Covidence systematic review software*, 2022), a software program that allows for collaborative review and data extraction. Two independent raters (EJ and CS) subsequently screened titles and abstracts by comparing each against the inclusion and exclusion criteria identified above. The full texts of studies included at the title and abstract screening stage were uploaded, and two independent raters read each paper in full, comparing each against the set of inclusion and exclusion criteria to determine eligibility. Conflicts arising during either of these stages were resolved by consensus. When the conflict could not be resolved using two independent raters, we sought the input of a third rater (CM).

**Data Extraction.** Using a custom data extraction form developed in Covidence (*Covidence systematic review software*, 2022), we extracted the following information from each included study: author(s); year of publication; study design; methodology; participant type (e.g., persons with mental illness, occupational therapists, parents, etc.); clinical characteristics of participants; number of participants; demographic characteristics of participants; country of authors; and level of participation. To determine the level of participation of persons with lived experiences of mental illness in each study, we used a framework introduced by Kindon et al.

(2007). This framework identifies key actions taken by researchers to involve persons with lived experience in a participatory study, and thus, provides an opportunity to measure the level of participation used in participatory studies. Further, Kindon et al. (2007) introduced five recurrent stages of action and reflection, including establishing relationships and a common agenda with all stakeholders; collectively designing research processes and tools; collaboratively analyzing the findings; working on feeding research back to all participants; and collectively identifying future research and impacts. We used the information provided by the authors of the included studies in the methodology section of each paper to identify whether they reported the process of action and reflection.

**Narrative Synthesis.** Qualitative content analysis (Graneheim & Lundman, 2004) was employed to code statements in the included studies pertaining to the research question using Dedoose (*Dedoose*, 2021), a qualitative data management program. This analysis involved reading through the full texts of the included articles to identify statements that were related to the research question. We then coded each statement inductively, followed by creating categories and sub-categories to generate themes and sub-themes that were related to the research question.

### Findings

The search yielded 1,311 citations. A total of 894 studies remained after removing 417 duplicates. 856 studies were eliminated during the title and abstract screening. We calculated Kappa statistics to assess the agreement among the raters for both the title and abstract screening and full-text review phases. Inter-rater reliability for the title abstract screening stage was 0.47, which demonstrates a "moderate" strength of agreement according to Ashby (1991). Thirty-eight articles were subjected to full-text review. For the full-text review phase, inter-rater reliability was 0.55, also demonstrating a "moderate" strength of agreement according to Ashby (1991). A total of 28 articles met the criteria for inclusion, and six studies were added from the reference lists of the included articles, which resulted in 34 studies in the final review. See Figure 1 for the summary of the study selection process and reasons for exclusion.

Of the 34 articles included in this review, 23 (76.4%) used qualitative methods, two (5.8%) studies used mixed methods, five (14.7%) were expert opinion papers, and one was a scoping review. Nearly half of the included studies (52.9%) were conducted in Canada and United Kingdom (nine studies each country), followed by the United States ( $n = 8$ ; 23.5%), Australia ( $n = 5$ ; 14.7%), Singapore ( $n = 1$ ; 2.9%), and South Africa ( $n = 1$ ; 2.9%), and internationally (North America, South America, Europe, and Africa) ( $n = 1$ ; 2.9%). Studies included in this review spanned from 1993 to 2022. A total of 22 (73.5%) studies were conducted after 2010. Twenty-two articles (64.7%) were published in occupational therapy journals, 11 (32.3%) in interdisciplinary journals, and one (2.9%)

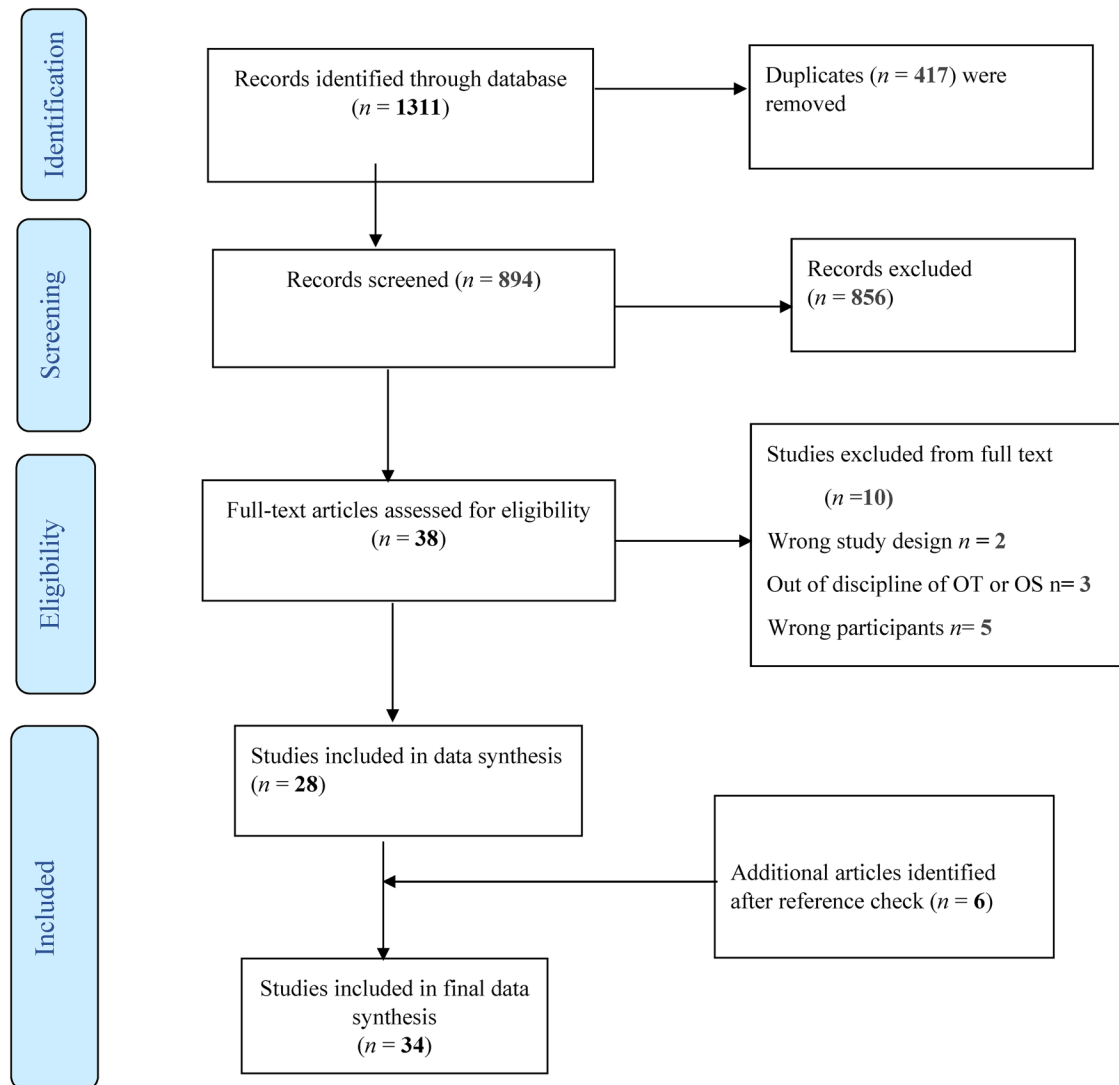


Figure 1. PRISMA diagram.

in an occupational science journal. The characteristics of individual studies included in this review are provided in Table 1.

The level of participation in the included empirical studies ( $n = 28$ ) according to the framework provided by Kindon (33) is provided in Figure 2. In 14 of the included studies (41.1%), the authors and participants collaboratively decided on the focus of the study. Fourteen studies (41.1%) collectively designed research processes and tools. In 12 of the included studies (35.2%), participants and researchers collaboratively analyzed the findings. Only four of the included studies (11.7%) collectively identified future research and impacts.

## Narrative Synthesis

We generated three themes in our content analysis: (a) coming together; (b) unique potentials of participatory research; and (c) challenges of conducting participatory research. Articles

associated with these themes and associated sub-themes are presented in Table 2.

**“Coming Together”.** The concept of “coming together” was explored in 23 articles (67.64%) in this review (see Table 2). Broadly, coming together can be defined as a context that brings experts by experience (mental health service users), experts by profession (service providers), and researchers who work together and share power to improve the experience of mental health service users. These articles noted that “coming together” is possible through (a) achieving a shared understanding and (b) effective communication.

**Achieving a Shared Understanding.** The value of achieving a shared understanding between persons with mental illness and service providers and researchers was discussed in 19 of the included studies in this review (See Table 2). Bryant (Bryant et al., 2012) believed that in the context of participatory

Table 1  
Description of the Included Studies (n = 34)

Authors	Study design	Methodology <sup>a</sup>	Methods	Types of participants <sup>a</sup>	Clinical characteristics of the sample	Number of participants	Demographic characteristics of the sample	Journal discipline	Country
Andonian (2010)	Qualitative	Participatory research	Photovoice	People with mental health issues	Bipolar affective disorder (n = 2)	5	<b>Age:</b> 21–56, <b>Gender:</b> n = 3 men; n = 2 women. <b>Race/ethnicity:</b> Caucasian (n = 3); Japanese and Filipina (n = 1); African American and Native American (n = 1). <b>LGBTQ2:</b> Unspecified	Occupational therapy	United States
Arblaster et al. (2018)	Qualitative	Participatory	Delphi method	Mental health consumers	Unspecified	14	<b>Age:</b> 20–59 <b>Gender:</b> n = 3 men; n = 11 women <b>Race/ethnicity:</b> Aboriginal (n = 1) <b>LGBTQ2:</b> Unspecified	Occupational therapy	Australia
Arblaster et al. (2019)	Qualitative	Participatory research approach	Interview	Mental health consumers	Unspecified	16	<b>Age:</b> 27–67 <b>Gender:</b> n = 7 men; n = 9 women <b>Race/ethnicity:</b> Aboriginal (n = 1); non-Aboriginal (n = 15) <b>LGBTQ2:</b> Unspecified	Occupational therapy	Australia
Baker and Procter (2014)	Qualitative	Participatory action research	Focus group	Occupational therapy and adults affected by mental illness	Major depression (n = 9); bipolar disorder (n = 7); anxiety disorder (n = 3); schizoaffective disorder (n = 2); borderline personality disorder (n = 2); schizophrenia (n = 2); obsessive compulsive disorder (n = 1)	16	<b>Age:</b> 39–59 <b>Gender:</b> n = 5 men; n = 11 women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Occupational therapy	Australia
Briken and Bryant (2019)	Reflection paper	Participatory research	Photovoice	Occupational therapy staff and service users from the acute mental health unit	Unspecified	Unspecified	Unspecified	Occupational therapy	United Kingdom
Bryant et al. (2010)	Qualitative		Focus group		Unspecified	At least ten	Unspecified	Interdisciplinary	United Kingdom

(continued)

Table 1  
Continued

Authors	Study design	Methodology <sup>a</sup>	Methods	Types of participants <sup>a</sup>	Clinical characteristics of the sample	Number of participants	Demographic characteristics of the sample	Journal discipline	Country
Bryant et al. (2012)	Qualitative	Participatory research	Researching Psychosis together group	Mental health service users and staff	Unspecified	8	<b>Age:</b> Unspecified <b>Gender:</b> $n = 3$ men; $n = 5$ women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Interdisciplinary	United Kingdom
Bryant et al. (2019)	Qualitative	Participatory research		People using local mental health services, an assistant, and an occupational therapist from local services, and an academician	Unspecified	Unspecified	Unspecified	Interdisciplinary	United Kingdom
Bryce (2012)	Qualitative	Auto ethnography	Photovoice	Mental health service users, occupational therapy students, health professionals, and academicians	Unspecified	Unspecified	Unspecified	Interdisciplinary	United Kingdom
Clark et al. (1993)	NA	Expert opinion		People receiving services from a specialist outreach mental health team	Unspecified	Unspecified	Unspecified	Occupational therapy	Canada
Anderson Clarke and Warner (2016)	Qualitative	Phenomenological research	Photovoice	Individuals diagnosed with mental illness	Depression ( $n = 1$ ); schizophrenia ( $n = 1$ ); bipolar ( $n = 1$ ); depression & anxiety ( $n = 1$ ); depression, schizophrenia, anxiety, substance abuse ( $n = 1$ ); personality disorder; depression, anxiety, intellectual disability ( $n = 1$ ); bipolar, anxiety, dissociative identity disorder ( $n = 1$ ); personality disorder, bipolar, depression, schizophrenia, anxiety ( $n = 1$ )	8	<b>Age:</b> 27-63 <b>Gender:</b> $n = 4$ men; $n = 4$ women <b>Race/ethnicity:</b> White ( $n = 5$ ); Black ( $n = 1$ ); White, Hispanic, and multiracial ( $n = 1$ ); Other ( $n = 1$ ) <b>LGBTQ2:</b> Unspecified	Occupational therapy	United States
Cockburn and Trentham (2002)	NA	Expert opinion	-	NA	NA	NA	NA	Occupational therapy	Canada
Dixon et al. (2022)	Qualitative	Participatory research	Photovoice	Women with mental health issues	Unspecified	12	<b>Age:</b> Unspecified <b>Gender:</b> All women <b>Race/ethnicity:</b> Unspecified	Interdisciplinary	Australia

(continued)



Table 1  
Continued

Authors	Study design	Methodology <sup>a</sup>	Methods	Types of participants <sup>a</sup>	Clinical characteristics of the sample	Number of participants	Demographic characteristics of the sample	Journal discipline	Country
Doll and Brady (2013)	Mixed Methods	Community-based participatory research	Focus group	Students recruited by teachers as potential risk for suicide	Unspecified	Unspecified	<b>LGBTQ2:</b> Unspecified <b>Age:</b> Unspecified <b>Gender:</b> Unspecified <b>Race/ethnicity:</b> All participants were Native Americans <b>LGBTQ2:</b> Unspecified	Occupational therapy	United States
Greco et al. (2017)	Qualitative	Narrative-phenomenology	Photovoice	Children in a school-based psychiatric setting	Attention deficit disorder; oppositional defiant disorder; conduct disorder; anxiety disorder; and/or learning delays	4	<b>Age:</b> 9–10 men; <i>n</i> = 2 women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Occupational therapy	Canada
Ingolia and Barrett (2019)	Qualitative	Participatory research	Photovoice	Mothers of children with complex trauma	Unspecified	6	<b>Age:</b> The mothers' ages ranged from young adulthood to middle age <b>Gender:</b> <i>n</i> = 6 women <b>Race/ethnicity:</b> ( <i>n</i> = 5) <b>Caucasian:</b> ( <i>n</i> = 1) Latina <b>LGBTQ2:</b> Unspecified	Occupational therapy	United States
Letts (2003)	NA	Expert opinion	-	NA	NA	NA	<b>Age:</b> Unspecified <b>Gender:</b> <i>n</i> = 8 men; <i>n</i> = 5 women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Occupational therapy	Canada
Makdasi et al. (2013)	Qualitative	Participatory research	Focus group	People with experience of psychosis, facilitated by service user researchers and an MSc student	Unspecified	13	<b>Age:</b> Unspecified <b>Gender:</b> <i>n</i> = 8 men; <i>n</i> = 5 women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Occupational therapy	United Kingdom
Maniam et al. (2016)	Qualitative	Participatory research	Photovoice	People who have been diagnosed with first-episode or at risk of psychosis	Schizophrenia ( <i>n</i> = 5); bipolar disorder ( <i>n</i> = 2); delusional disorder with OCD ( <i>n</i> = 1); psychosis not otherwise specified ( <i>n</i> = 1); at risk ( <i>n</i> = 2)	11	<b>Age:</b> 21–38 <b>Gender:</b> <i>n</i> = 4 men; <i>n</i> = 7 women <b>Race/ethnicity:</b> Unspecified	Occupational therapy	Singapore

(continued)

Table 1  
Continued

Authors	Study design	Methodology <sup>a</sup>	Methods	Types of participants <sup>a</sup>	Clinical characteristics of the sample	Number of participants	Demographic characteristics of the sample	Journal discipline	Country
Mirza et al. (2008)	Qualitative	Participatory action research	Focus group	People with psychiatric disabilities	Unspecified	8	<b>LGBTQ2:</b> Unspecified <b>Age:</b> All the participants were middle-aged <b>Gender:</b> <i>n</i> = 6 men; <i>n</i> = 2 women <b>Race/ethnicity:</b> 7 African Americans ( <i>n</i> = 7), 1 Caucasian ( <i>n</i> = 1)/ Black ( <i>n</i> = 7); White ( <i>n</i> = 1) <b>LGBTQ2:</b> Unspecified	Interdisciplinary	United States
O'Brien et al. (2021)		Scoping review	Arksey and O'Malley's framework	NA	NA	NA	NA	Interdisciplinary	Australia
Pettican et al. (2021)	Qualitative	Participatory action research	World Café events	Persons who experience mental distress	Unspecified	23	<b>Age:</b> Unspecified <b>Gender:</b> <i>n</i> = 21 men; <i>n</i> = 2 women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Occupational science	United Kingdom
Pettican et al. (2022)	Qualitative	Participatory action research	World Café events	Persons who experience mental distress	Unspecified	8	Unspecified	Occupational therapy	United Kingdom
Rempfer and Knott (2002)	NA	Expert opinion	NA	NA	NA	NA	NA	Occupational therapy	United States
Russinova et al. (2018)	Qualitative	Participatory research	Photovoice	Persons with mental health challenges	Schizophrenia spectrum disorder ( <i>n</i> = 13)	43	<b>Demographic characteristics of the sample</b> <b>Age:</b> <40 (28%), 40–55 (35%), <55 (37%) <b>Gender:</b> <i>n</i> = 13 men; <i>n</i> = 30 women <b>Race/ethnicity:</b> White ( <i>n</i> = 31), not White ( <i>n</i> = 12) <b>LGBTQ2:</b> Unspecified	Interdisciplinary	United States
Schwartz et al. (2013)	Qualitative	Participatory action research and narrative	Focus group	Five consumers of mental health services, three	Unspecified	10	Unspecified	Interdisciplinary	Canada

(continued)

Table 1  
Continued

Authors	Study design	Methodology <sup>a</sup>	Methods	Types of participants <sup>a</sup>	Clinical characteristics of the sample	Number of participants	Demographic characteristics of the sample	Journal discipline	Country
Schwartz et al. (2020)	Qualitative	phenomenological methodology Participatory research	Stakeholder-engaged approach	occupational therapists, one psychiatrist, and a clinician-researcher affiliated with a university Mental health clinicians (n = 10), peer providers (n = 9), and transition specialists (n = 20)	3 had diagnoses of autism spectrum disorder and anxiety and/or depression (n = 3); diverse intellectual/developmental disabilities and mental health conditions (n = 3)	39	<b>Age:</b> Unspecified <b>Gender:</b> n = 6 men; n = 33 women <b>Race/ethnicity:</b> white (n = 33); African American (n = 3); Asian (n = 1); other (n = 2) <b>LGBTQ2:</b> No one had non-binary/other gender identities	Interdisciplinary	United States
Shaffer et al. (2020)	Mixed methods	Pre-test, post-test pilot design, and a participatory action approach	Interview	Parents of special needs children	Unspecified	11	<b>Age:</b> 20–59 <b>Gender:</b> n = 11 women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Interdisciplinary	North America (5), South America (2), Europe (1), Africa (3)
Smith and Suto (2014)	Qualitative	Community-based participatory research	Interview, Focus group	Patients in acute psychiatry units	Unspecified	7	<b>Age:</b> Early 20 s to Late 60s <b>Gender:</b> n = 5 men; n = 2 women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Occupational therapy	Canada
Suto et al. (2021)	Qualitative	Community-based participatory research	Focus group, interview, aping activities	Individuals living with serious mental illness and/or addictions	ADHD, anxiety disorder, bipolar disorder, depression, schizoaffective disorder, schizophrenia, substance misuse	23	<b>Age:</b> 32–67 <b>Gender:</b> n = 15 men; n = 8 women <b>Race/ethnicity:</b> Unspecified <b>LGBTQ2:</b> Unspecified	Occupational therapy	Canada
Suto and Smith (2014)	Qualitative	Community-based participatory research	Interview, focus group	Acute-based mental health professionals	Unspecified	8	Unspecified	Occupational therapy	Canada
Townsend et al. (2000)	Qualitative	Ethnography + Participatory research	Interview	People with long-term mental illness	Unspecified	Average attendance has ranged from 8 to 12	Unspecified	Occupational therapy	Canada

(continued)

Table 1  
Continued

Authors	Study design	Methodology <sup>a</sup>	Methods	Types of participants <sup>a</sup>	Clinical characteristics of the sample	Number of participants	Demographic characteristics of the sample	Journal discipline	Country
Tsatsi and Plastow (2021)	Qualitative	Participatory action research	Interview	Mental health care users	Unspecified	9 participants per meeting	<b>Age:</b> Unspecified <b>Gender:</b> All men <b>Race/ethnicity:</b> All black Africans <b>LGBTQ2:</b> Unspecified	Occupational therapy	South Africa
Wimpenny et al. (2010)	Qualitative	Participatory action research	Focus group	Occupational therapists	Unspecified	15	Unspecified	Occupational therapy	United Kingdom

<sup>a</sup>Terminologies/descriptions are based on the information provided in the specific papers.

Authors		Andonian (2010)	Arblaster et al. (2018)	Arblaster et al. (2019)	Baker & Procter (2014)	Birken & Bryant (2019)	Bryant et al. (2010)	Bryant et al. (2012)	Bryce (2012)	Clarke & Warner (2016)	Dixon et al. (2022)	Doll & Brady (2013)	Greco et al. (2016)	Ingolia & Barrett (2019)	Makdisi et al. (2013)
<b>Phase 1<sup>1</sup></b>															
<b>Action</b>	Establish relationships and common agenda with all stakeholders	✓	✓	✓	-	✓	✓	✓	✓	-	-	✓	-	✓	✓
	Collaboratively decide on issues	-	✓	-	-	✓	✓	✓	-	-	-	✓	✓	-	✓
<b>Reflection</b>	On research design, ethics, knowledge, and accountability	✓	✓	-	-	✓	✓	✓	✓	✓	-	-	✓	✓	✓
<b>Phase 2<sup>1</sup></b>															
<b>Action</b>	Build relationships	✓	-	-	✓	✓	✓	✓	✓	-	-	✓	-	-	✓
	Identify roles and responsibilities	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	-	✓	✓
	Collectively design research processes and tools	-	✓	-	-	✓	✓	✓	✓	-	-	✓	-	-	-
	Discuss potential outcomes	-	-	-	-	-	-	-	-	-	-	-	-	-	-
<b>Reflection</b>	On research questions, design, working relationships, and information required	-	✓	-	-	✓	✓	✓	✓	-	-	-	-	-	✓
<b>Phase 3<sup>1</sup></b>															
<b>Action</b>	Work together to implement research and collect data	✓	✓	✓	-	✓	✓	✓	✓	-	✓	-	✓	✓	✓
	Enable participation of all members	✓	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Collaboratively analyse findings	-	✓	✓	-	✓	-	✓	-	-	-	-	-	-	-
	Collaboratively plan future actions	✓	-	-	-	✓	-	-	-	-	-	-	✓	✓	-
<b>Reflection</b>	On working together	-	-	-	-	-	✓	✓	✓	-	-	-	-	✓	-
	Has participation worked?	-	-	-	-	-	✓	✓	✓	-	-	-	✓	✓	-
	What else do we need to do?	-	-	-	-	-	-	✓	✓	-	-	-	✓	-	-
<b>Phase 4<sup>1</sup></b>															
<b>Action</b>	Begin to work on feeding research back to all participants and plan for feedback on process and findings	-	✓	-	-	✓	✓	✓	-	✓	✓	-	-	✓	-
<b>Reflection</b>	Evaluate both the action and reflection processes as a whole	-	-	-	-	-	✓	-	✓	-	-	-	-	-	-
<b>Phase 5<sup>1</sup></b>															
<b>Action</b>	Collectively identify future research and impacts	-	-	-	-	-	✓	-	-	-	-	-	-	✓	-
Authors		Maniam et al. (2016)	Mirza et al. (2008)	Pettican et al. (2021)	Pettican et al. (2022)	Russinova et al. (2018)	Schwartz et al. (2013)	Schwartz et al. (2020)	Shaffer et al. (2020c)	Smith & Suto (2014)	Suto et al. (2021)	Suto & Smith (2014)	Townsend et al. (2000)	Tsatsi et al. (2021)	Wimpenny et al.
<b>Phase 1<sup>1</sup></b>															
<b>Action</b>	Establish relationships and common agenda with all stakeholders	-	✓	✓	✓	-	✓	✓	-	✓	✓	✓	✓	✓	✓
	Collaboratively decide on issues	-	✓	✓	✓	-	✓	-	✓	-	✓	-	✓	-	-
<b>Reflection</b>	On research design, ethics, knowledge, and accountability	-	✓	✓	✓	-	-	-	-	✓	✓	✓	✓	✓	✓
<b>Phase 2<sup>1</sup></b>															
<b>Action</b>	Build relationships	-	✓	✓	✓	-	-	✓	-	✓	✓	-	✓	✓	-
	Identify roles and responsibilities	-	✓	✓	✓	✓	-	✓	-	-	✓	-	✓	-	-
	Collectively design research processes and tools	-	✓	✓	✓	-	✓	✓	-	-	✓	-	✓	✓	-
	Discuss potential outcomes	-	✓	-	-	-	✓	✓	-	-	-	-	✓	-	-
<b>Reflection</b>	On research questions, design, working relationships, and information required	-	✓	✓	✓	-	✓	-	-	✓	✓	✓	✓	✓	✓
<b>Phase 3<sup>1</sup></b>															
<b>Action</b>	Work together to implement research and collect data	-	✓	✓	✓	-	✓	✓	-	-	✓	-	✓	✓	✓
	Enable participation of all members	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Collaboratively analyse findings	-	-	✓	✓	-	✓	✓	-	-	-	✓	✓	✓	✓
	Collaboratively plan future actions	-	✓	-	-	-	✓	✓	✓	-	✓	✓	-	-	-
<b>Reflection</b>	On working together	-	✓	-	-	-	-	-	-	-	-	-	✓	✓	✓
	Has participation worked?	-	✓	-	-	-	-	-	-	-	-	-	✓	✓	✓
	What else do we need to do?	-	✓	-	-	-	-	-	-	-	-	-	✓	✓	-
<b>Phase 4<sup>1</sup></b>															
<b>Action</b>	Begin to work on feeding research back to all participants and plan for feedback on process and findings	-	✓	✓	✓	✓	✓	✓	-	-	✓	-	✓	✓	-
<b>Reflection</b>	Evaluate both the action and reflection processes as a whole	-	-	-	-	-	-	-	-	-	-	-	✓	✓	✓
<b>Phase 5<sup>1</sup></b>															
<b>Action</b>	Collectively identify future research and impacts	-	-	-	-	-	-	-	-	-	-	-	✓	✓	-

Figure 2. Level of participation of the included studies (N = 28).

research, both occupational therapists and persons with mental illnesses have something to learn, and involving all stakeholders in research creates space for all to learn from each other and achieve a shared sense of purpose. In Maniam's study (2016), photovoice as a participatory method was identified as a unique tool for occupational therapists to hold dialogs with

their clients. The findings of eight studies found that there is a mismatch between the priorities and goals of people accessing mental health services and the focus of occupational therapy mental health services themselves (Anderson Clarke & Warner, 2016; Arblaster et al., 2018; Birken & Bryant, 2019; Ingolia & Barrett, 2019; Mirza et al., 2008; Rempfer &

Knott, 2002; Schwartz et al., 2013; Shaffer et al., 2020). Schwartz et al. (2013) pointed out that the conflict between values of beneficence in medical ethics increases the tension between the occupational therapist and consumer values. In Arblaster's study (2018), it was discussed that occupational therapists usually value clinical reasoning and evidence-based interventions, while mental health consumers want therapists to understand and value their perspective and support their choice. Arblaster et al. (2018) found that "consumer's emphasis on human connection and 'doing with', and a therapist's emphasis on 'doing to'." The participants in Arblaster's study (2018) believed that human connection is a core value that underpinned the recovery-oriented occupational therapy practice. Several studies ( $n = 11$ ) clearly expressed the need for

service providers such as occupational therapists to better understand the needs of persons with mental illness and validate their stories in practice and research (Arblaster et al., 2018; Baker & Procter, 2014; Bryant et al., 2012; Bryant et al., 2019; Bryce, 2012; Doll & Brady, 2013; Makdisi et al., 2013; O'Brien et al., 2021; Schwartz et al., 2013; Schwartz et al., 2020; Suto et al., 2021). Collaborative relationship (Arblaster et al., 2019; Bryant et al., 2012; Suto et al., 2021), learning from lived experiences (Arblaster et al., 2018; Baker & Procter, 2014; Makdisi et al., 2013), professional self-reflection, critically examining power inequity (Arblaster et al., 2019), being open to different knowledge (Bryant et al., 2019), and using co-design protocols (O'Brien et al., 2021) were mentioned as strategies to build up a shared understanding of

Table 2  
Themes and Sub-Themes Represented by the Included Studies

Theme	Sub-themes	Studies included
Coming together ( $n = 23$ )		Arblaster et al., 2018; Arblaster et al., 2019; Baker & Procter, 2014; Birken & Bryant, 2019; Bryant et al., 2010; Bryant et al., 2012; Bryant et al., 2019; Bryce, 2012; Anderson Clarke & Warner, 2016; Doll & Brady, 2013; Ingolia & Barrett, 2019; Makdisi et al., 2013; Maniam et al., 2016; Mirza et al., 2008; O'Brien et al., 2021; Rempfer & Knott, 2002; Schwartz et al., 2013; Schwartz et al., 2020; Shaffer et al., 2020; Smith & Suto, 2014; Suto & Smith, 2014; Suto et al., 2021; Tsatsi & Plastow, 2021
	Achieving a shared understanding ( $n = 19$ )	Arblaster et al., 2018; Arblaster et al., 2019; Baker & Procter, 2014; Birken & Bryant, 2019; Bryant et al., 2012; Bryant et al., 2019; Bryce, 2012; Anderson Clarke & Warner, 2016; Doll & Brady, 2013; Ingolia & Barrett, 2019; Makdisi et al., 2013; Maniam et al., 2016; Mirza et al., 2008; O'Brien et al., 2021; Rempfer & Knott, 2002; Schwartz et al., 2013; Schwartz et al., 2020; Shaffer et al., 2020; Suto et al., 2021
	Effective communication ( $n = 10$ )	Arblaster et al., 2019; Bryant et al., 2010; Bryant et al., 2012; Bryant et al., 2019; O'Brien et al., 2021; Schwartz et al., 2013; Schwartz et al., 2020; Smith & Suto, 2014; Suto & Smith, 2014; Tsatsi & Plastow, 2021
Unique potentials of participatory research ( $n = 23$ )		Andonian, 2010; Arblaster et al., 2019; Bryant et al., 2010; Bryant et al., 2012; Bryant et al., 2019; Bryce, 2012; Anderson Clarke & Warner, 2016; Clark et al., 1993; Cockburn & Trentham, 2002; Dixon et al., 2022; Doll & Brady, 2013; Greco et al., 2017; Ingolia & Barrett, 2019; Letts, 2003; Maniam et al., 2016; O'Brien et al., 2021; Pettican et al., 2021; Pettican et al., 2022; Rempfer & Knott, 2002; Russinova et al., 2018; Townsend et al., 2000; Tsatsi & Plastow, 2021; Suto et al., 2021
	Empowerment ( $n = 13$ )	Andonian, 2010; Bryant et al., 2010; Bryant et al., 2012; Bryant et al., 2019; Anderson Clarke & Warner, 2016; Cockburn & Trentham, 2002; Greco et al., 2017; Ingolia & Barrett, 2019; Maniam et al., 2016; Rempfer & Knott, 2002; Suto et al., 2021; Townsend et al., 2000; Tsatsi & Plastow, 2021
	Sharing power ( $n = 10$ )	Bryant et al., 2010; Bryant et al., 2019; Bryce, 2012; Clark et al., 1993; Cockburn & Trentham, 2002; Greco et al., 2017; Letts, 2003; O'Brien et al., 2021; Rempfer & Knott, 2002; Townsend et al., 2000
	Stigma resistance ( $n = 4$ )	Bryant et al., 2019; Rempfer & Knott, 2002; Russinova et al., 2018; Townsend et al., 2000
	Expressing what matters ( $n = 14$ )	Arblaster et al., 2019; Andonian, 2010; Bryant et al., 2010; Bryce, 2012; Clark et al., 1993; Dixon et al., 2022; Doll & Brady, 2013; Greco et al., 2017; Maniam et al., 2016; Pettican et al., 2021; Pettican et al., 2022; Rempfer & Knott, 2002; Townsend et al., 2000; Tsatsi & Plastow, 2021
Challenges of conducting participatory research ( $n = 11$ )		Andonian, 2010; Bryant et al., 2010; Bryant et al., 2012; Bryant et al., 2019; Cockburn & Trentham, 2002; Letts, 2003; Maniam et al., 2016; Rempfer & Knott, 2002; Townsend et al., 2000; Tsatsi & Plastow, 2021; Wimpenny et al., 2010

issues related to mental illness in occupational therapy literature.

**Effective Communication.** Considerations for effective communication between mental health consumers and occupational therapists were discussed in ten participatory studies (see Table 2). Participants in four studies (Arblaster et al., 2019; Bryant et al., 2019; Smith & Suto, 2014; Suto & Smith, 2014) suggested that occupational therapists need to engage in self-reflection to find effective ways of building a therapeutic alliance with persons living with mental illness. The value of informal and non-clinical communication style in the context of participatory projects was identified as a priority in three studies (Bryant et al., 2012; Schwartz et al., 2020; Tsatsi & Plastow, 2021). Being a co-researcher in a non-clinical context was important for changing how everyone communicated (Bryant et al., 2012). Some participants felt that communication would be easier if professionals could “just take off their labels and see what’s going on” (Schwartz et al., 2013, p. 115). In contrast, some service providers believed that setting clear boundaries and expectations can foster trust between mental health consumers and service providers (Schwartz et al., 2020). Building culturally sensitive relationships with co-researchers before starting the co-design research projects was also highlighted in O’Brien’s study (2021).

### “Unique Potentials of Participatory Research”

Twenty-three articles (67.6%) included in this review identified the unique potential of participatory research for individuals who experience mental illness (see Table 2). The findings of these articles were divided into the following sub-themes: (a) empowerment; (b) sharing power; (c) expressing what matters; and (d) stigma resistance.

**Empowerment.** The experience of collaborating in participatory research created a potential feeling of empowerment for occupational therapy service users in 13 studies (see Table 2). Having an opportunity to learn from each other, expand the sense of meaning, become more vocal, share expertise with a greater audience, improve self-efficacy, feel a sense of mastery and achievement, achieve acceptance and hope, and take action towards facilitating change in their environment were factors provided in the context of participatory research that helped participants feel empowered (Andonian, 2010; Bryant et al., 2012; Bryant et al., 2019; Maniam et al., 2016; Rempfer & Knott, 2002; Tsatsi & Plastow, 2021).

**Sharing Power.** Ten of the included studies demonstrated that power could be shared between individuals with mental illness, mental health professionals, and researchers through conducting participatory studies where the traditional roles of “patient” *versus* “professional” are broken down (see Table 2). In Greco’s study (2017), children living with mental illness had the opportunity to take control using photovoice methods, which reduced the power imbalance between

children, adults, and researchers. Townsend et al. (2000) suggested that occupational therapists and other professionals need to extend the notion of person-centredness in the context of research in order to reduce power inequity.

**Stigma Resistance.** Participatory research was identified as a potential tool to resist stigma for persons with mental illness in four studies (see Table 2). These studies highlighted the potential of participatory research to increase the knowledge of stigma, and advocate against it. In particular, Russinova et al. (2018) suggested that photovoice was a transformative tool to reduce the impact of prejudice and discrimination toward persons with mental illness and can translate the experience of stigma by presenting it both visually and conceptually. Russinova et al. (2018) believed that photovoice allows persons with mental illness to express their experiences of stigma in a way that feels psychologically safe.

**Expressing What Matters.** Fourteen of the included articles pointed out that participatory approaches enable individuals living with mental illness to express what really matters to them to create relevant and meaningful knowledge (see Table 2). Three of the included studies (Pettican et al., 2021; Pettican et al., 2022; Tsatsi & Plastow, 2021) suggested that involving persons with mental illness in conducting research can assist both mental health consumers and mental health professionals such as occupational therapists to identify important ideas and the desired direction for change. In two studies, authors (Dixon et al., 2022; Rempfer & Knott, 2002) noted that including the voice of mental health consumers helps occupational therapists access the knowledge not represented in the scientific literature. Arblaster et al. (2019) suggested using participatory methods within the field of occupational therapy to ensure that focus of occupation is balanced with the lived experience concerns of persons living with mental illness. Greco et al. (2017) believed that the participatory philosophy of the photovoice method can help children with mental health disorders who use occupational therapy services to generate new domains for self-report measures and report what matters to them.

### “Challenges in Conducting Participatory Research”

The challenges of conducting participatory research were documented in 11 (32.3%) of the included studies (see Table 2). One of the concerns noted by two authors (Bryant et al., 2019; Letts, 2003) was the process for obtaining ethical approval for studies in which service user researchers were also the subjects. In Bryant’s study (2019), a university was unfamiliar with the idea of service user co-investigators, and there were mutual misunderstandings throughout the process of seeking ethical approval. Townsend (2000) believed that expectations of research policies, ethical and funding guidelines, and research presentations and publications create barriers to the inclusion of persons living with mental illness and minimize experiential knowledge. The idea of involving

service users in research was described as difficult to achieve because the majority of participatory research agendas are determined by academicians and/or service providers, not service users (Bryant et al., 2010). Finding common ground (Bryant et al., 2019), finding the focus of research (Townsend et al., 2000), and disagreement about ownership (Bryant et al., 2019) and leadership (Letts, 2003) of the project were described as challenges associated with conducting participatory research. Two of the included studies made the point that participatory research is time-consuming and needs more resources than the traditional research methods (Letts, 2003; Rempfer & Knott, 2002). In one study, maintaining the enthusiasm and involvement of people accessing mental health services in all project stages became a concern (Cockburn & Trentham, 2002).

In four studies, participants also experienced individual challenges with the participatory projects in which they were involved (Bryant et al., 2010; Bryant et al., 2012; Cockburn & Trentham, 2002; Maniam et al., 2016). Fear and anxiety during focus groups (Bryant et al., 2012), being unfamiliar with the occupation of research (Bryant et al., 2010), being an active decision-maker (Cockburn & Trentham, 2002), fear of being judged, technical difficulties such as working with a camera (in the instance of photovoice), and fear of not completing the project (Maniam et al., 2016) were reported. Participants in Tsatsi's study (2021), believed that their involvement in the scientific part of the research process was limited because they were only involved in the outcome formulation, initial data analysis, and taking action. Andonian (2010) discussed that selection bias in participatory approaches is assumed because the participants willing to be involved in research projects and have an active role might be different from those not comfortable speaking in group settings.

## Discussion

This scoping review aimed to identify the range of research exploring participatory approaches with persons living with mental illness within the fields of occupational therapy and occupational science. Our findings suggest that involving persons with lived and living experiences of mental illness in all stages of the research process can provide several benefits, for all people involved in the research, including researchers, health professionals, and mental health consumers, while also introducing some challenges. The role of co-design and providing opportunities for persons with mental illness to take on leadership roles in health system planning, evaluation, and research is critical for contributing to efforts aimed at reconciling the historical oppression faced by this population. This includes creating the opportunity to identify important research questions, share knowledge, and participate in all stages of the research process, including analysis, interpretation of results, and mobilizing findings into practice and policy, as these are common practices in participatory approaches. However, our review also found barriers to conducting this type of research with this population, including time to do the research and work within institutional

challenges that prevent such studies taking place in the first place. We encourage future occupational therapy and occupational science research to document these challenges and propose solutions for the field for how best to navigate institutional challenges, such as ethics/human resources and funding.

The findings of participatory research included in this review highlighted the risk of misalignment between mental health consumers' priorities and service providers' goals in practice and research. In one of the included studies in this review, Arblaster et al. (2018) found that human connection and "doing with" are emphasized by mental health consumers, while the focus of mental health professionals is "doing to." This is consistent with the existing literature, which suggests that occupational engagement of individuals is motivated by the need to belong and connect with others (Andonian & MacRae, 2011; Berger, 2011). We believe that this misalignment should be addressed by working alongside persons who experience mental illness to generate a shared understanding of mental illness and effective approaches for service provision. In research, occupational therapists and occupational scientists can address a historical lack of collaboration with service users by bringing together researchers, service providers, and persons with lived experiences to generate relevant occupation-focused research questions. This suggestion builds on recommendations in previous studies, which suggest that mental health consumers and mental health professionals need to work together to achieve a shared understanding of diagnosis, prognosis, and recovery (McCabe et al., 2013; Papageorgiou et al., 2017).

The findings of this review reveal the unique potential of participatory research for persons living with mental illness. In this review, participants felt empowered by engaging in research projects and being active decision-makers. Clark et al. (1993) believed that involving persons in occupational therapy research is supported by values of occupational therapy practice, in which involvement in decision making is crucial. Given the complexities of environments in which participatory research is conducted, this review suggests that occupational therapy researchers should apply a pragmatic approach that aligns with the core assumptions, principles, and values of occupational therapy (Ikiugu & Schultz, 2006). By doing so, they can effectively support the self-determination of individuals living with mental illness and provide opportunities for practicing social justice.

Collective empowerment aims that characterize participatory research are congruent with occupational therapy's aim to enable empowerment through occupation (Townsend et al., 2000).

This study also demonstrates that research can be an important occupation for marginalized populations such as persons living with mental illness. There is an opportunity to conduct participatory research focused specifically on the occupational injustices faced by this population and identifying opportunities for mitigating these injustices in collaboration with persons with lived experience of mental illness. Considering research as an occupation can be important specifically for occupational scientists who study the concept of occupation itself and it can shed light on the ideas of occupation that are usually taken for granted. In Townsend's study (2000) focused on the clubhouse



model, research was considered a meaningful occupation involving three opportunities for exploration: data collection and analysis, education, and action. Research as an important occupation was also discussed by Law (1997), who notes that providing opportunities for individuals to participate in the occupation of research may be considered as an important role for occupational therapists in community development (Law, 1997).

Our review also demonstrates that the experience of being a co-researcher may be challenging for persons living with mental illness.

Being unfamiliar with occupation of research (Bryant et al., 2010), fear and anxiety during the focus groups (Bryant et al., 2012), and technical difficulties are examples of challenges that persons living with mental illness experience as they engage in participatory studies (Maniam et al., 2016). It is important for occupational therapy and occupational science researchers and practitioners to consider the challenges that persons living with mental illness may face in the context of conducting participatory research and identify strategies for addressing some of these challenges to improve the experience for persons with lived experiences. Furthermore, if we want to engage persons living with mental illness in participatory research, we need to be willing to share power and control with persons with lived experiences as co-researchers.

Participatory research as a way of resisting stigma has the capacity to reveal the deeper psychological layers in the subjective experience of the stigma of mental illness and promote stigma resistance. The role of participatory research in promoting stigma resistance among persons with lived experiences of mental illness is documented in the literature (Rudnick, 2012; Whitley et al., 2020). Whitley et al. (2020) pointed out that participatory research is a feasible anti-stigma intervention and could be an effective means of stigma reduction. Rudnick (2012) also believed that stigma is a social injustice and argued that stigma could be decreased by involving persons with mental illness in the research process in which the expertise of these individuals is respected. There is a need within the field of occupational therapy and occupational science to consider the potential of participatory research to mitigate the traumatic impact of stigma among persons living with mental illness.

### Implications for Practice

Occupational therapy literature highlights that mental health consumers should be central to decision-making, and their choice should underpin their recovery process (Arblaster et al., 2018; Birken & Bryant, 2019). Participatory approaches align closely with recovery principles, which highlight the need for learning from lived experiences (Arblaster et al., 2019). Occupational therapy and occupational science could benefit from conducting research alongside persons with lived experiences in identifying occupational issues relevant to their lives, and in the co-design of novel interventions that are relevant and meaningful in the lives of persons living with mental illness.

Occupational therapists can find opportunities to collaborate with researchers and persons with lived experiences in conducts of participatory studies. We believe that investigating both the potentials and limitations of doing participatory research with mental health consumers will be insightful for researchers and it helps to achieve a more practical understanding of the participatory research approach.

### Implications for Research and Policy

Future occupational therapy and occupational science research in mental health should focus on conducting studies that involve persons with mental illness in the research and that provide refinements to practice. As the popularity of participatory methodologies grows, it is important to include critical reflection to find ways to overcome the obstacles and issues. It is worth mentioning that, in most of the included studies, participants were not engaged in all stages of the research. While it is challenging to incorporate all elements of participatory research into a single project (Gray et al., 2000), optimal outcomes can be achieved when occupational therapists and scientists embrace the values and principles of participatory research, ensuring a balanced power dynamic that maximizes the meaningful involvement of participants across all stages of the study.

There is also a need for policies at the university level to facilitate the process of conducting participatory research and avoid delays in obtaining ethical approval for projects where participants are also co-researchers. Funding opportunities are also needed for participatory projects to provide necessary resources to extend the use of participatory approaches in diverse settings and with diverse persons. We also need policies that support involving persons living with mental health in the design of new and re-design of the existing occupational therapy services to enhance the relevance of practice.

### Limitations

Several limitations in this study are acknowledged. First, we acknowledge that we could not distinguish between studies of varying degrees of quality by conducting a scoping review because scoping reviews do not involve a critical appraisal of included studies or the aggregation of data. Second, we reported the level of participation in the included studies based on the information provided by the authors. There is a possibility that some information related to the process of action and reflection in the included studies has been deleted due to word limitations. Third, although all the included studies were within the field of occupational therapy or occupational science, most of the authors did not discuss how participatory research can inform occupational therapy or occupational science. Fourth, the first author analyzed the data (EJ). She identifies as a Muslim woman without the lived experience of mental illness and recognizes that these social locations may have influenced the way that she analyzed and interpreted the findings of the included studies. Finally, most of the studies included in this review did not provide demographic characteristics of the

participants such as clinical characteristics, disability, race, ethnicity, or the 2SLGBTQ+ status. As a result, it would be difficult to comment on the ways in which the demographic characteristics of co-researchers in participatory projects impact the process of conducting research.

## Conclusion

The findings of this study underscore the importance of participatory research within the field of occupational therapy and occupational science with persons with lived and living experiences of mental illness. Involving individuals living with mental illness in all stages of research can help to shape the mental health system to become one that is more relevant, effective, and compassionate by incorporating the wisdom of persons with mental illness in its design and ongoing refinement. The findings of this study suggest that participatory approaches have been increasingly adopted by occupational therapy and occupational science to maximize the possibility that occupation-based services are relevant and meaningful for persons with mental illness. We hope that the findings of this review provide insights for researchers, practitioners, and persons with lived experiences about the use of occupation-focused participatory methods with persons living with mental illness and stimulate novel ideas for using these approaches with marginalized groups more commonly.

## Key Messages

- Participatory research by persons living with mental illness and occupational therapists can influence service delivery and design.
- Further investigation of the potential and challenges of occupation-focused participatory research could increase practical understanding.

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## Supplemental Material

Supplemental material for this article is available online.

## ORCID iDs

Elham Javadizadeh  <https://orcid.org/0009-0002-4340-0445>

Skye Barbic  <https://orcid.org/0000-0002-7076-2452>

Carrie Anne Marshall  <https://orcid.org/0000-0002-0592-7716>

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### Author Biographies

**Elham Javadizadeh** is a PhD candidate in Health and Rehabilitation Science program at Western University. She completed her bachelor's and Master of Science degrees in occupational therapy at Tehran University of Medical Science and the University of Social Welfare and Rehabilitation Sciences respectively. Throughout her career, she has worked in various healthcare settings, including hospitals, rehabilitation centers, and private clinics. Her research interests include mental health, health promotion, homelessness, occupational science, international students' mental wellbeing. Her current research interests focus on graduate students' mental wellbeing.

**Abram Oudshoorn** is an Associate Professor and Associate Director (Graduate Programs) at The Arthur Labatt Family School of Nursing, Western University and the Arthur Labatt Family Chair in Nursing Leadership in Health Equity. Professor He holds cross appointments with Lawson Health Research Institute and the Department of Psychiatry, Western University, as well as serving as a member of the Centre for Research on Health Equity and Social Inclusion (CRHESI). Teaching interests include community health, mental health, global health, research methods/statistics, and advanced Nursing theory. His research interests include homelessness prevention, intersectional understandings of homelessness, homelessness globally, program evaluation, health promotion, refugee housing outcomes, critical ethnography, qualitative methods, participatory action research, poverty and health, critical theory, mental health, and others. His research informs health and social systems and builds health equity to support housing stability for vulnerable populations.

**Lori Letts** is a Professor in the School of Rehabilitation Science. She received her Bachelor of Science degree in Occupational Therapy from the University of Western Ontario. After working as an occupational therapist in general rehabilitation, long term care, and with clients in the community,

she returned to graduate school. In 1991, she received a Master of Arts with a joint degree in Gerontology and Regional Planning and Resource Development. Her thesis examined environmental influences on the functional abilities of older adults. Following that, she worked as Researcher with Community Occupational Therapists and Associates in Toronto and was also the Assistant National Coordinator of the CAOT Seniors' Health Promotion Project. She completed doctoral studies in the Faculty of Environmental Studies at York University in 2002. The focus of her doctoral dissertation was on the use of participatory research and community organizing as means to promote health with older adults in the city of Toronto.

**Skye Barbic** is an Assistant Professor in the Department of Occupational Science and Occupational Therapy at the University of British Columbia (UBC), where she completed her second postdoctoral fellowship. She completed her first postdoctoral fellowship at the Centre for Addiction and Mental Health in Toronto, where she developed a comprehensive measure of personal recovery for people with serious mental health conditions such as schizophrenia.

**Chelsea Shanoff** received her Master of Science degree in Occupational Therapy from the University of Western Ontario. She also holds a Doctoral of Musical Arts degree (2020) from the University of Toronto, with a thesis titled "Playing-Related Injuries and Posture among Saxophonists". She works as an occupational therapist with community partners to ensure patients have a high-quality level of care when moving throughout the healthcare system.

**Carrie Anne Marshall** is an Assistant Professor and Director of the Social Justice in Mental Health Research Lab in the School of Occupational Therapy at Western University. Her research focuses on intersections between poverty and mental health, with a particular focus on homelessness among persons living with mental illness (including substance use disorders). Her teaching interests and experience include courses related to psychosocial determinants of occupation and health, and counselling and group therapy for graduate-level occupational therapy students. These teaching interests build on Professor Marshall's clinical background in mental health, where she has worked as an occupational therapist on assertive community treatment teams, early intervention in psychosis, crisis teams, and in the corrections and forensic mental health system.