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Research Article

A Scoping Review on The Delivery of a Co-Produced Module on Psychosis to Service Users/Family and Supporters

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Abstract

Key objectives: To document and describe the array of supports available for those with psychosis, their family members, and supporters. To establish best practice as it pertains to psychosis, particularly at crisis and recovery [personal and clinical]. **Methods:** The scoping review methodology used was guided by the Johanna Briggs Institute Reviewer Manual and Arksey and O'Malley (2005) framework [1]. Three electronic databases (the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ovid PsycINFO and Ovid Medline were searched in addition to the Bielefeld Academic Search Engine (BASE) which was searched for grey literature in the field. 10,298 records were screened against review eligibility criteria. **Results:** Only one study met the inclusion criteria for this scoping review. **Conclusions:** Most studies at the full text stage were excluded because they were the wrong population. The populations in the excluded studies were a mixed serious mental illness population. For example, participants were frequently a mix of people diagnosed with schizophrenia, bipolar disorder, and major depression. The participants of interest to the scoping review were a population with a clinical diagnosis of psychosis only. We recommend that future research be undertaken to design and evaluate interventions that should clearly outline the population of interest, namely, service users with a clinical diagnosis of psychosis. The focus should not be on a mixed population because supports and services offered across the different illnesses may differ in their effectiveness. Supports and services should be tailored to the population of interest only.

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Key words: Psychosis; Recovery; Families; Caregivers; Supports; Scoping review

Introduction

Overview of Psychosis

Psychosis is a deteriorating and disabling illness with up to 80% of patients experience a relapse or hospitalisation within the first five years of the diagnosis [2]. Thus, early interventions to treat psychosis are important given that the first five years is a critical period to prevent relapse. The Irish Early Intervention in Psychosis Clinical Programme published its Model of Care in 2019. The aim of this Model of Care (Health Service Executive [HSE] 2019) [3] was to develop services for adolescents and adults (14 to 65 years of age) experiencing a first episode psychosis with the aim of minimising delays in accessing services and specialised treatment to prevent relapse, promote recovery and contribute to better health outcomes such as improved functioning and quality of life [4,5].

Clinical Features

Psychosis is typically characterised by an inability to perceive reality, manifesting in delusions, defined as false fixed beliefs, bearing no semblance to reality and hallucinations defined as a distortion of sensory perceptions to include visual (seeing things that are not there), olfactory (smelling things that are not there), tactile (feeling things that are not there), gustatory (tasting things that are not there) and auditory (hearing things that are not there) hallucinations [6]. The symptoms of psychosis induce elevated levels of distress and disability in the person with the illness, their family, and carers.

Fleeting mild psychotic experiences are common, like anxiety or depression [3]. They are reported by 15 to 17 per cent of the general population [7,8]. It is when the psychotic experiences become intense, persistent, or distressing that they are of clinical significance. Psychotic disorders are classified as mental disorders, using the International Classification of Mental Disorders (ICD 11) (World Health Organisation [WHO], 2019) [9] and the Diagnostic and Statistical Manual 5th Edition (DSM V) [6].

Improved outcomes in psychosis are associated with early recognition of symptoms, timely initiation of evidence-based treatment approaches with a focus on recovery (National Health Service [NHS] [10], England, the National Collaborating Centre for Mental Health [NCCMH] and the National Institute for Health and Care Excellence [NICE], 2016) [11]. Antipsychotic medications are the recommended the first line of treatment for psychosis, but treatment approaches should not be limited to medication only. Other approaches such as psychological treatments also need integration into the individual's treatment plan and where appropriate should be inclusive of family members and caregivers [11].

Causes of Psychosis

There is no one specific cause of Psychosis. Psychopathology is categorised by a wide group of distressing cognitive, emotional, and behavioural symptoms that affect the individual's capacity to function in society [12]. These can include but are not limited to changes in mood, perception, poor memory or processing of information, agitation, or catatonia.

In more current times pathophysiological models believe that psychotic symptoms are caused by a dysregulation of dopaminergic activity in the brain, a theory that is strongly linked to the unexpected finding of the first effective antipsychotic treatments in the 1950s.

In recent years, having access to modern neuroimaging techniques has significantly expanded the understanding of the connections between genetic influence and environmental factors [12]. Thus, allowing for greater understanding but more complications in ensuring effective and appropriate treatment.

Each person will have his or her own unique experience of the development, course, and outcome of the treatment of psychosis. Evidence has established that genetic makeup is a risk factor (Schizophrenia Working Group of the Psychiatric Genomics Consortium [SWGPGC], 2014) [13]. As well as genetics, there are other established risk factors including birth trauma, early developmental injuries, neurodevelopment conditions, childhood traumas, low IQ, ethnicity, migration, and substance use, specifically cannabis. Other risks include sleep deprivation or stress [3]. These specific risk factors do not work alone and usually involve a multitude of risk factors.

Historical Context

Historically, psychotic disorders place the greatest burden on mental health services as well as having the worst outcomes for an individual and families/carers. These outcomes include high rates of involuntary detention in mental health hospital settings, delay in accessing treatment, extended hospital stays, poor engagement with support services, re-current relapses, co-morbidities with other mental health illnesses and substance use, suicidal and incomplete recovery from the illness. Harrison et al., [14] have emphasised the importance of the available supports and treatments within the first 2.5 years for the psychotic illness on the long-term outcome for both individuals and families/carers.

The role of families and carers in the context of psychosis has become an essential component through the development of research and effective therapies. Through this development of the family intervention in psychosis, there have been decreases in relapse for the individual experiencing psychosis as well as a reduction in hospital admissions. A systematic review by Claxton et al., (2017) [15] identified an overall improved life functioning for the individual also. This review also showed positive outcomes for families and carers including the reduction of negative communication and frustration and anger towards the individual. By engaging in the therapy, families felt more supported and able to support their loved one. Reducing family burden through family interventions has also been shown to be effective [16].

To that end, the person with psychosis, their families and caregivers must be informed about best practice approaches for the management of psychosis at all stages of the illness.

For the purpose of this manuscript, psychosis is defined as follows:

'The misperception of thoughts and perceptions that arise from the patient's own mind/imagination as reality, and includes delusions and hallucinations' [17].

Materials and Methods

The methodologically rigorous scoping review framework, as proposed by Arksey and O'Malley (2005) [1] was chosen for this review. The five stages of the scoping review process are detailed below.

Stage 1: Research Aim and Objectives

The aim was to provide an overview of psychosis. The objectives were as follows:

- To document and describe the array of supports available for those with psychosis, their family members, and supporters
- To establish best practice as it pertains to psychosis, particularly at crisis and recovery [personal and clinical]

Stage 2: Identification of relevant studies

The scoping review of the literature was undertaken systematically and reported according to the Preferred Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews [PRISMA-ScR] checklist [18,19] and Joanna Briggs Institute [JBI] Reviewers Manual [20].

Inclusion Criteria

Participants

This scoping review considered studies that focus on adults (18 years old and older) with a clinical diagnosis of psychosis using the DSM-IV or DSM-V (APA 2013), ICD-10, or ICD-11 (WHO 2019) [9] where psychosis describes the misperception of thoughts and perceptions that arise from the patients' own mind/imagination as reality and includes delusions and hallucinations [17].

Concept

The concepts of interest were the support for persons with psychosis, their family members, and caregivers especially when a person is in crisis and aiming for recovery.

Context

This review considered studies from any inpatient clinical care setting or community/home care setting, where participants have been hospitalised and for any length of time and where the participants have received discharge care. Studies were included regardless of country or origin or sociocultural setting.

Types of Sources

Primary research studies such as randomised controlled trials (RCT's), controlled clinical trials (CCT's), cohort studies, case series, case reports, manuals, and clinical practice guidelines were eligible for this scoping review if they considered the current best practice of psychosis at crisis and recovery or any of the current array of supports available for persons with psychosis, their family members, or caregivers. Papers written in English only were included (for practicality) however, it is acknowledged that some valuable resources written in other languages may have been missed as a result.

Search Strategy

We conducted the search strategy in 2 phases:

In the **first** phase, we created preliminary searches to be run in Ovid Medline and PsycINFO using keywords provided by review team members. A selection of eligible articles (see eligibility criteria in section 3) retrieved from these preliminary searches were mined for further appropriate keywords and controlled vocabulary. Using these keywords and controlled vocabulary, we developed a search strategy in Ovid Medline.

In the **second** phase, we reviewed the Medline strategy according to Peer Review of Electronic Search Strategy (PRESS) guidelines [21] and adapted it for use in the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Ovid Psyc [20,22]. The Bielefeld Academic Search Engine (BASE) was searched for grey literature in the field [22]. The literature search between Augurst 17th and 20th 2022. All databases searched were from inception to the date on which searches were run and limited to English language only (Table 1).

Searches were also designed to be run in Cochrane CENTRAL, Embase and Ovid APA Psycarticles but the volume of records returned was too large to screen within the limited time period and resources allocated to this project. Ovid APA Psycarticles was not available for use at the time when searches were carried out.

In addition, we consulted with service users and experienced mental health professionals, working in this area to locate further eligible studies or relevant material.

Finally, we screened the reference lists of eligible articles identified through the literature search and conduct hand searches of relevant journals to optimise the comprehensiveness of the strategy.

We exported database search results into EndNote X9 and removed duplicates. We imported the remaining results into Rayyan [23] for screening against eligibility criteria and repeated the de-duplication exercise.

Stage 3: Study Selection

Evidence screening and selection

Level 1 (title and abstract screening). Two reviewers (LM and SS) independently screened the titles and abstracts. A third review author (FJ) resolved disagreements. We pilot-tested this screening phase on a sample of 10% of the retrieved titles and abstracts.

Level 2 (full-text screening). Two review authors working independently undertook the full-text screening (FJ and CK) who retrieved full-text articles from the level one screening phase against the eligibility criteria as above. Conflicts were resolved by discussion between the two reviewers or by a discussion with a third review author (SS). We also pilot-tested this screening phase on a sample of 10% of potentially eligible full-text articles.

We maintained a chart of the screening process that documents the flow of articles from the search findings to the number of full-text articles that we finally included in this review. We recorded the number of titles/abstracts and full-text articles excluded through de-duplication and screen failure. We documented the citations of excluded full-text articles along with reasons for their exclusion. The PRISMA flow diagram (Figure 1) outlines the results of the literature search. The scoping review framework used was able to facilitate the inclusion of an array of literature, including both qualitative and quantitative studies.

Stage 4: Charting data

We developed a data charting form a priori. Two reviewers reviewed a 10% sample of the final full-text publications to validate the consistency and accuracy of the data charting form. Discrepancies were resolved by discussion between both reviewers (SS and LM) with the intervention of a third reviewer (FJ) when necessary.

This was an iterative process, and we made modifications to the charting form as required. We contacted the authors of the primary studies to request missing or more data if required. Once all reviewers agreed on the definitive version of the charting form, a single reviewer completed data extraction. A second reviewer verified extracted data. Data from the included article was organised into a table (Table 2).

Stage 5: Collating, summarising, and reporting results

We presented charted data in terms of descriptive analysis. Descriptive analysis entailed numerical calculations of frequency to display the extent, nature and distribution of the article included in this scoping review. More specifically, we focused this analysis on the country of origin, study design, data analysis/synthesis, demographic characteristics of the sample, and characteristics of the reported support tools and constituents of best practice. This descriptive analysis identified the predominant research methods and geographical locations in the literature.

Results

This section presents the results of the search which are presented in Table 1 and Figure 1.

Database	Pre-Deduplication	Post EndNote Deduplication
Medline	5908	5899
Psych Info	7623	3586
CINAHL	700	429
BASE	1153	693
Total	15384	10607

Table 1: Record of Searches.

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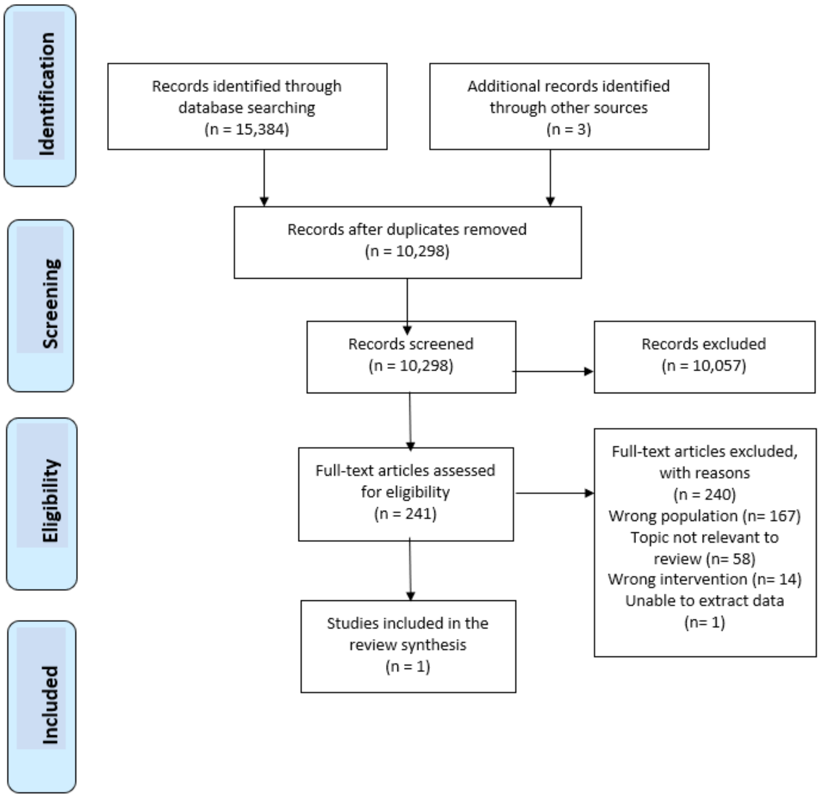

Figure 1: PRISMA Flowchart.

Source adapted from Moher et al. (2009) [24]- The PRISMA Group - Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Summary of the search

Database searches retrieved 15,384 citations. After duplicate removal, we screened 10,298 titles and abstracts and deemed 10,057 studies to be irrelevant. We obtained the full text for 241 studies. We excluded 240 studies with reasons outlined in the PRISMA flowchart (Figure 1). Only one study met the inclusion criteria.

Descriptive summary of the included study

Only one study met the inclusion criteria. Chein et al., (2022) [25] carried out a multi-centre three-arm randomised controlled trial across six integrated Community Centres of Mental Wellness in Hong Kong to explore the effects of a four-month peer-facilitated self-management intervention (PFSMI) for Chinese patients with recent onset psychosis (ROP) (n=59) compared with a psychoeducation group (PEG) (n=58) and treatment-as-usual (TAU) group (n=55). The PFSMI and PEG consisted of 10 weekly/biweekly, 1.5-hour sessions over four months in comparison to TAU, which consisted of routine community mental healthcare services and psychiatric outpatient care. Validated instrument tools were utilised at 1-week and 6-months post interventions to measure levels of recovery, improvement in problem-solving ability, insight into illness/treatment, functions and reducing psychotic symptoms. When compared with the psychoeducation group (PEG), the PFSMI did not show significant differences in improving recovery at 1-week post-intervention. Most of the study outcomes in the PFSMI (QPR, SLOF, PANSS, and ITAQ) were significantly better than the PEG at the 6-month follow-up. This indicates that peer-facilitated, problem-solving-based training in illness self-management can provide more sustainable benefits as an early intervention for ROP than the psychoeducation group program. The findings of this study support that PFSMI can produce medium-term positive effects on the mental health and functioning of patients with ROP. It is worth noting that a lack of comparison and identification of differences in socio-demographic, clinical characteristics and baseline outcome measure scores between the participants and non-participants makes it difficult to generalise the findings to the ROP population. In addition, the PFSMI consisted of three main components (peer support, problem solving, and self-management), which make it difficult to identify one key element that attributed to the effectiveness of the PFSMI.

Author(s), Year, Title, Place	**Aim and methodology**	**Population, methods**	**Supports/ Intervention**	**Summary of findings**	**Key messages**	**Limitations**
Chien et al., (2022) A randomised controlled trial of a peer-facilitated self-management program for people with recent-onset psychosis.	To test the effects of a four-month peer-facilitated self-management intervention (PFSMI) for Chinese patients with recent onset psychosis (ROP) compared with a psychoeducation group (PEG) and treatment-as-usual (TAU) group.	Total: 172 participants with a clinical diagnosis of psychosis for ≤5 years (ROP)	A four-month peer-facilitated self-management intervention (PFSMI) for patients with ROP compared with a psychoeducation group (PEG) and treatment-as-usual (TAU) group across six Integrated Community Centers for Mental Wellness.	The findings indicate that a recovery-focused, self-management program facilitated by peer support workers, with a guided personal recovery plan/ booklet, can be an effective early intervention program in facilitating or improving ROP patients' recovery by enhancing their illness self-care, with increasing peer support.	The findings support that PFSMI can produce medium-term positive effects on the mental health and functioning of patients with ROP.	Participants were not blinded to the behavioural intervention owing to its nature.
	Study design: A multi-centre, three-arm Randomised Controlled Trial (RCT) of a community-based PFSMI, with a repeated measure parallel groups design.	Participants were randomly assigned to the following 3 groups: PFSMI (n=59), PEG (n=58) or TAU (n=55).	The PFSMI & PEG consisted of 10 weekly/ biweekly, 1.5-hour sessions over four months.	When compared with the psychoeducation group (PEG), the PFSMI did not show significant differences in improving recovery at 1-week post-intervention.	The 4-month PFSMI, in addition to routine community mental healthcare services, can assist people with recent-onset psychosis to improve recovery, symptom severity, functioning, and insight into illness/ treatment, thus reducing their re-hospitalizations/ relapses.	The PFSMI consisted of three main components (peer support, problem-solving, and self-management), which make it difficult to identify one key element that may be attributed to the effectiveness of the PFSMI.

Hong Kong		Outcomes measured using surveys at 1-week and 6- month post-intervention – level of recovery (QPR*); improvement of problem-solving ability (SPSI-R:S*); insight into illness/treatment (ITAQ*); and functioning (SLOF*); and reducing psychotic symptoms (PANSS*) and rehospitalisation rates.	The TAU group consisted of monthly psychiatric consultations and treatments prescribed by psychiatrists, nursing advice on community care, brief education about mental illness and its care by psychiatric nurses, home visits by case managers, and/or referrals to social welfare and employment support services.	Most of the study outcomes in the PFSMI (QPR, SLOF, PANSS, and ITAQ) were significantly better than the PEG at the 6-month follow-up. This indicates that peer-facilitated, problem-solving-based training in illness self-management can provide more sustainable benefits as an early intervention for ROP than the psychoeducation group program.		The consistency of peer support (amount and intensity) among the PFSMI participants outside of group sessions was not assessed or controlled for by the research team.
						A lack of comparison and identification of differences in socio-demographic, clinical characteristics and baseline outcome measure scores between the participants and non-participants makes it difficult to generalise the findings to the ROP population.
Tools*: ITAQ - Insight and Treatment Attitude Questionnaire; SLOF - Specific Level of Functioning Scale; SPSI-R:S - Specific Level of Functioning Scale; PANSS - Positive and Negative Syndrome Scale; QPR - Questionnaire about the Process of Recovery						

Table 2: Data from Included Articles.

Discussion of Findings

The objective of this scoping review was to identify psychoeducational and psychosocial interventions for service users with a clinical diagnosis of psychosis and their caregivers/ supporters to inform the development of an psychosis educational module. One study met the inclusion criteria of the review.

Strengths and limitations

The main limitation of this review is that only one study met our eligibility criteria, so the generalisability of its findings is limited. It is possible that had we included search results from all databases, more eligible studies could have been located. Conversely, from a strengths point of view, the methods undertaken in this scoping review followed a rigorous and systematic approach. The population of interest in the review were carefully considered and clearly defined at the outset. Findings from the included study, [25], a well-designed randomised controlled trial, demonstrated that a peer-facilitated self-management programme for early onset psychosis was effective in the management and recovery.

Most of the studies assessed for inclusion in this review were excluded because of the 'wrong population.' The demographics tables or description of study participants, presented in the full-text studies, detailed the inclusion of mixed populations in terms of the serious mental illnesses studied. The main serious mental illnesses described included schizophrenia, schizoaffective disorder, depression, and bipolar disorder. Psychosis was often used as an umbrella term for multiple serious mental illnesses. A population of study participants with a clinical diagnosis of psychosis only was established in the individual studies reviewed.

Consultation with service users with experiences of psychosis and advocacy groups for this population argued that psychosis is a clinical diagnosis in itself. It is not reasonable to conclude that people with psychosis are the same in terms of illness, management, and recovery approaches as other serious mental illnesses like schizophrenia.

The one study included in this review clearly defined the population of interest. Participants had a clinical diagnosis of psychosis, suggesting that it is possible to distinguish between this and other mental illnesses. This is important because psychoeducation and psychosocial interventions can be more targeted and focus on a specific population. This lends itself to a more comprehensive evaluation of the effectiveness of interventions in a given population and will inform best practice approaches.

Further Research ad Recommendations

We recommend that future research to evaluate the effectiveness of interventions should clearly outline the population of interest, namely in this scoping review, service users with psychosis. Chien et al., (2022) [25] have demonstrated that this is possible.

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Patient and public involvement

This review was developed in collaboration with individuals who availed of mental health services. The fact that the research team includes the service user involvement is an added advantage when it comes to contextualising the findings.

Ethical Considerations

Ethical approval was not required as scoping reviews use data from already published studies, which have gone through their own ethical review process. However, the researchers ensured data integrity, honesty and transparency throughout the scoping review process which are ethical imperatives in research.

Conflict of Interest

The authors report that there is no conflict of interest. The authors alone are responsible for the content and writing of this manuscript.

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