

Exploring lived experience of recovery processes in those with schizophrenia: A systematic review with thematic synthesis of qualitative evidence

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Abstract

The purpose of the study was to conduct a systematic review of literature which explores lived experiences of the manifestation, appearance of meaning, and interpretation of the recovery process in schizophrenia. Recovery as a lived experience in schizophrenia is an idiosyncratic and debated process that emerges from the perspectives of people who experience schizophrenia. Recovery literature is gained from qualitative accounts and synthesising these accounts provides an overview of the evidence base for recovery. A search of Medline, Emcare, Cinahl and Scopus databases discovered 11 studies that were published between 2016–2020 that met the scope of the review. Studies were included if they used qualitative methodology to explore how individuals with schizophrenia experience the process of recovery. Studies were subjected to quality assessment using the Critical Appraisal Skills Program (CASP) Qualitative Research Checklist. Several themes were identified during the qualitative analysis. These themes were linked by a common thread. This “meta-theme” is “connection.” Connection with individual sense of self and connecting with the social world. Connecting with self enhance the capacity of those with schizophrenia to be able to connect interpersonally and intersubjectively with the social world, which is seen to lead to recovery. The reviewed literature supported the theoretical approach that the person with schizophrenia needed to regain their lost self before taking further steps in the recovery process. Further research of schizophrenia as a self – disorder being phenomenologically designed would further highlight the necessity of this for the recovery process. Such research would illuminate recovery being about who you are and not about how sane or normal you are.

1. Introduction

The World Health Organisation (WHO) describes schizophrenia as a serious mental disorder which affects around 26 million people worldwide (WHO 2008). It can be persistent as well as recurrent (Ko et al. 2013). The characteristics of this illness are disturbances of perception, thought, emotion and behaviour (Ko et al. 2013). Mental health providers are increasingly tasked with providing recovery-oriented treatment (Lee et al. 2020). Historically, education and training of mental health providers has tended to focus more on schizophrenia being a neurobiological, permanent condition where the person with this disability has little hope of returning to full functioning (Feiner and Frese 2009). Mental health recovery has become popular, especially focused on the process of recovery, as an alternative to historic medication-centred approaches to treating schizophrenia.

This review complements existing knowledge by reviewing approaches that indicate recovery is a holistic lived experience that cannot be meaningfully achieved by taking anti-psychotic medication alone. Medication is an important contribution toward the enhancement of recovery and is one of many factors that contribute to the lived experience of a person in recovery. Patricia Deegan, a researcher with lived experience of schizophrenia, argues that recovery depends on the person with schizophrenia being able to reclaim and recover a sense of self (Deegan 1988). Deegan suggests the subjective aspects of schizophrenia are paramount to recovery. This can be about becoming who you are rather than trying to evaluate how sane or how normal you can be (Deegan et al. 2008). Recovery is now understood to be both a possibility and the goal of mental health treatment (Anthony 1993). Recovery is a dynamic evolving and unique process within the life of each person faced with schizophrenia's challenges. It is not an end point or achievement but a way of living and a constant choice that a person in pursuit of recovery makes (de Wet et al. 2015). Being a choice highlights the entitlement of the basic human right of all individuals with or without a mental illness. The person with schizophrenia can choose to be in recovery and not remission. They are entitled to receive adequate care and the right to make individual choices. By recovering the sense of self, the person with schizophrenia can become stronger, confident, and powerful as an autonomous and self-determining human being better able to make such choices (Bejerholm and Roe 2018).

Autonomy and self-determination enable the person with schizophrenia to take control of their life and claim the right to become who they are. This contrasts with traditional models that apply subject independent criteria to determine if an individual is normal or sane and for which the individual perspective is out of the scope of the model – disqualified in the case of schizophrenia by diagnostic definitions of unreliability due to psychosis. The qualitative, subjective, lived experience of recovery for people with schizophrenia highlights how disenfranchisement and disconnection, caused by being externally assessed and evaluated, compartmentalised, and judged, diminishes the potential for meaningful recovery. This is because it distances them from the essential human need for connection and socially meaningful interaction that is required to be able to identify as a healthy, functioning human being.

Recovery is oriented towards the process of developing new meaning and purpose in life. The evaluation of this is troublesome if it is solely focused on external evaluations of productivity and conformity to externally defined standards created by people who do not have the experience of schizophrenia. This does not have to be employment, it can be education and/or physical activity that adds value to the unique experience of the person with schizophrenia (Anthony 1993). As recovery is a unique and subjective process it can also be exciting because the processes are self-defined and challenge assumptions about normality (Bejerholm and Roe 2018). This may be especially significant for those with a serious mental illness, who are not accustomed to self-identifying as 'normal.' The process of interacting socially for those with this illness to form, maintain or even cease relationships can help develop new meaning and purpose as the person with schizophrenia grows over and beyond the catastrophic effects of their illness. Recovery processes involve a change of attitude, values, feelings, goals, skills and/or roles (Anthony 1993). This can be attitude toward the diagnosis of schizophrenia, or revaluing of the self, feeling empowered, having future goals, understanding that recovery is possible, and honing skills for sustaining internal / social connectedness and exploring/managing new-found roles and identity.

2 Methods

A review protocol exists and can be accessed from Prospero. No. CRD42020214483

2.1 Aim

The aim was to review literature where the researcher explores the manifestation and appearance of meaning and interpretation of the recovery process in schizophrenia.

2.2 Research question

How do those individuals with schizophrenia experience the process of recovery?

2.3 Study eligibility

The review considered studies that conformed to the following criteria:

- a) focused on qualitative data.
- b) the primary aim was exploring recovery from the lived experience perspective. In other words, examining respondent subjective interpretations about recovery.
- c) the respondents were diagnosed with schizophrenia.
- d) respondents were adults.
- e) studies were in English language
- f) studies contained primary source information from research respondents who were making sense of their experiences in the recovery process of schizophrenia.

2.4 Exclusion criteria

Studies were excluded if they were examining recovery in those with organic psychosis, post-partum psychosis or substance misuse disorders as these have distinctive characteristics to schizophrenia. Purely quantitative studies were also excluded.

2.5 Search criteria and procedures

The search was conducted on the 28th of August 2020 by the Primary Investigator (PI) and a research librarian from James Cook University, Nguma-bada, Australia. Medline, Emcare, Cinahl and Scopus databases were used to search for studies published between 2016–2020. These search engines were chosen to ensure extraction across both medical and psychological journals. Search modes were Boolean/Phrase. Combinations of the following key words were used in the search: A) *Medline*: 1) "exp schizophrenia spectrum and other psychotic disorders"/ or psychotic disorders.mp., 2) (interview* or experience* or qualitative).mp., 3) recovery.mp., 4) 1 and 2 and 3, 5) limit 4 to year = "2016–2020", 6) exp Communications Media/, 7) 5 and 6; B) *Emcare*: 1) exp schizophrenia spectrum disorder/, 2) exp social media/, 3) recovery.mp, 4) *personal experience/, 5) 1 AND 2 AND 3 AND 4, 6) 1 AND 3 AND 4, 7) limit 6 to year = "2016–2020"; C) *Cinahl*: 1) (MH "Psychotic Disorders+"), 2) (MH "Recovery"), 3) (MH "Interviews") OR experience*/ OR qualitative, 4) (MH "Interviews") OR experience*/ OR qualitative) AND (S1 AND S2 AND S3), 5) (MH "Interviews") OR experience*/ OR qualitative) AND (S1 AND S2 AND S3) with date limit to year = "2016–2020", 6) (MH "Blogs") AND recovery AND mental; and D) *Scopus*: 1) (interview*) OR (experience*) OR (qualitative), 2) (interview* OR experience* OR qualitative) AND (recover*), 3) (interview* OR experience* OR qualitative*) AND (recover*) AND (schizophren* OR psycho*), 4) (interview* OR experience* OR qualitative) AND (recover*) AND (schizophren* OR psycho*) AND (social AND media), 5) (interview* OR experience* OR qualitative) AND (recover*) AND (schizophren* OR psycho*) AND (social AND media) AND date limit to year = "2016–2020"

Literature identified in the search was extracted and reference lists were explored. There were 25 searches carried out in total across the four databases.

2.6 Data management and screening

A PRISMA process (Liberati et al. 2009) was followed for the management of the screening and filtering of the findings of the searches. All results from the database searches were entered into the referencing management software program Endnote, which was used to group results by database source and to identify and remove duplicates. The initial screening to determine relevance was made by comparing the titles and abstract content to the inclusion /exclusion criteria.

2.7 Data extraction and analysis

The primary author extracted the data on study characteristics. This was cross-checked by the secondary author for consistency and conformity with the research aims and criteria. The study characteristics are described and presented in Table 1. Analysis was guided by the thematic synthesis of qualitative research approach. This type of synthesis focuses on the synthesis of qualitative studies using thematics (Wood and Alsawy 2018). The findings of this review were coded and explored for analytical themes and concepts. It was necessary to make decisions regarding the use of thematic synthesis in a reliable and valid manner. The critical realist perspective of Braun and Clarke (2006) was employed for this purpose. Coding was done manually and occurred at a semantic level. This was because the data presented within individual studies was already subject to diverse methods of qualitative analysis. The process of exploring each study became an iterative process that called upon the reflection of the researcher to make connections between and within studies. This entailed utilising the essences of the quotes from lived experience of the respondents with schizophrenia regarding recovery processes. It was the patterns, resemblances, and regularities from respondent experiences in the studies, that were chosen for analysis to reach the conclusions of the experiences given to the process of recovery in schizophrenia. Braun and Clarke (2006) suggest that researchers could use the following five steps for analysis:

Table 1
Study Characteristics.

Publication	Aim	Country	Study Characteristics	Method of Analysis	Themes
Sangeorzan, et al. (2019).	Investigate experiences of people self-identified with schizophrenia who video log (vlog) about their illness on YouTube.	England	Thirty respondents. Nine respondents self-identified as having schizophrenia. Ages not stated.	Interpretative Phenomenological Analysis (IPA)	1) Minimising isolation 2) Vlogging as therapy 3) Fighting stigma
Tuffor, et al. (2020).	To explore how religion influences recovery from mental illness.	England	Twelve respondents aged 19–57 years. Semi-structured interviews. Eleven respondents with schizophrenia. Lived experience.	(IPA).	1) Pentecostilism 2) African healing systems
Hargreaves, et al. (2017).	To explore the meaning of individual experiences of physical activity(PA) in people with schizophrenia in recovery.	England	Eight respondents. Aged 18–65. Lived experience of schizophrenia.	Hermeneutic phenomenology.	1) Not ready to engage 2) Initial steps to engaging in PA 3) Becoming more active 4) Doing PA
Ngubane, et al. (2019).	Aim was to explore the experiences and meanings of recovery for women living with schizophrenia	England	Fifteen respondents. Lived experience of schizophrenia.	(IPA)	1) Emotionality 2) Pain 3) She is mad ignore her 4) Being better.
Gray & Deane, (2016).	To highlight how internal struggles are complicated for people with first episode psychosis regarding medications.	England	Twenty respondents. Aged to 35years with schizophrenia. Lived experience.	Thematic analysis	1) The drugs do work 2) The drugs don't work 3) Side effects 4) Indirect effects of medication 5) Rage against the machine 6) Not trivial issues about medication.
Williams, et al. (2018).	Explore how service users experienced viewing lived experience videos as well as its influence on recovery.	Australia	Thirty-six service users with experience of website use. Lived experience of schizophrenia.	Grounded theory	1) Being inspired, 2) Knowing not alone, 3) Believing recovery is possible
Sumskis, et al. (2017).	Understand meaning of resilience as described by people with schizophrenia.	Australia	Fourteen respondents with schizophrenia. Lived experience.	Psychophenomenological Method	1) Dynamic of support and challenge experiences of schizophrenia.
De Jager, et al.(2016).	The importance of services to be sensitive to the differing styles of a person's recovery and their readiness for change.	Australia	Eleven respondents. Semi-structured interviews. Lived experience.	Narrative inquiry	1) Despair/ exhaustion

Publication	Aim	Country	Study Characteristics	Method of Analysis	Themes
Lee, et al: (2020).	Point out the importance of self-efficacy, emotion management, and social giving in recovery process without medication	United States of America.	Nineteen respondents. In-depth interviews. Lived experience.	Grounded theory.	1) Hope, 2) Lived experience recovery via multiple pathways 3) Holistic approach 4) Social, family and community support 5) Strengths (themes that relate to internal and external processes in recovery).
Peter & Jungbauer (2019).	Investigate how those with mental illness experience psychiatric label	Germany	Sixteen adult respondents. Five with schizophrenia. Lived experience.	Grounded Theory	1) Diagnosis: concealing or revealing

1 Familiarisation with the review studies.

2 Generation of initial codes

3 Searching for themes

4 Review themes

5 Defining and naming of themes

Braun and Clarke (2006) acknowledge steps are not followed sequentially. It became apparent that the data was directing the primary investigator rather than a predefined theoretical model in this instance, and that this was a suitable modification of the method, based on an inductive approach to analysis. Such bottom-up thinking is central to qualitative research where subjectivity and meaning are a characteristic of inductive reasoning according to Seale (2012) and Creswell (2013).

2.8 Quality appraisal

As the review was qualitative by nature each included study was subjected to the Critical Appraisal Skills Programme (2019) (CASP). The CASP is a tool for assessing the applicability, reliability, and validity of published qualitative research according to ten criteria.

1 Aim of research

2 Methodology

3 Design

4 Recruitment

5 Data collection

6 Relationship between researcher and respondents

7 Ethics

8 Data analysis

9 Findings

10) Value of research

The CASP tool assists in the gaining of insight along with understandings that can extend or enhance the effectiveness of results and/or point to future effectiveness studies. It can be used to compliment the Effective Public Health Practice Project (2015) (EPHPP) Quality Assessment Tool for Quantitative Studies where studies use mixed methods. There were mixed method studies in the current review, but this tool was not used in conjunction with the CASP as

quantitative mixed method aspects of included papers were outside scope. The CASP was used for the qualitative aspects of the included studies. Qualitative studies were the focus of the review. The CASP tool enhanced trustworthiness. This was employed alongside the general exclusion criteria incorporated in the review used by the PI. The CASP was employed to verify the credibility and dependability of the included papers. This was cross-checked by the secondary author of the review and an additional independent academic.

3 Results

The search identified 478 results within the date limit of 2016–2020 and five from other sources for a total of 483 articles (Fig. 1). After removal of 100 duplicates 383 studies remained. Assessment of study titles led to 291 being excluded. The abstracts of the remaining 92 studies were then screened by the PI and 74 further studies were excluded on this basis. From the remaining 18 studies, seven studies were excluded on reading the article content in full. 11 studies remained to be included in the final analysis. The reasons for the removal of the seven studies and the 365 irrelevant items from the search return of 383 was varied. Qualitative studies can be viewed as being jealously guarded in terms of their trustworthiness (Creswell 2013). The screening process is important. Many studies were excluded due to being quantitative in focus rather than qualitative. Studies were also excluded due to being originally published before 2016. The other exclusion factors were by age group (inclusion of non-adults), substance induced psychosis, diagnosed across the full schizophrenia spectrum and not specifically diagnosed with schizophrenia alone and no discussion of recovery processes. There were also studies that referred to the structure of hallucination and delusion from a theoretical perspective.

3.1 Study Characteristics

The Study Characteristics Table (Table 1.) shows studies were completed in England (4), Australia (3), Germany (1), Scandinavia (1), United States of America (1) and Poland (1). The publication date range was 2016–2020: two in 2020 (Lee et al.; Tuffor) along with three in 2019 (Ngubane et al.; Peter et al.; Sangeorzan et al.) one study in 2018 (Williams et al.), two studies in 2017 (Hargreaves et al.; Sumskis et al.) and three studies from 2016 (de Jagger et al.; Gray and Deane; Nowak et al.).

The review identified a total of 11 qualitative studies with 209 respondents. Of these 209 individuals 86 were specifically diagnosed with schizophrenia alone from eight studies (Hargreaves et al. 2017 (4); Lee et al. 2019 (6); Ngubane et al. 2019 (15); Nowak et al. 2017 (28); Peter and Jungbauer 2019 (5); Sangeorzan et al. 2019 (8); Sumskis et al. 2017 (14); Tuffour 2013) (6)). The 123 respondents that remained were not specifically labelled as schizophrenic. Gray and Deane (2016) reject the diagnosis of schizophrenia by referring to psychosis for their sample of 20 respondents. Williams et al. (2018) also preferred to use psychosis to identify their 36 study respondents. The remaining 67 were specified as respondents having a serious mental illness (SMI). The ages of respondents ranged from 18 years (Nowak et al. 2016) to 65 years of age (Hargreaves et al. 2017). To ensure the quality of the research, the characteristics of the included papers were cross-checked by the secondary author of the review. No anomalies were found.

3.2 Thematic Classification

The Thematic Classification of Publications Table 2. shows four themes generated from a possible 35. Eight of the 11 included studies found medication to be important in the recovery process. Five studies saw relationship with self and the social world as being important. Six studies saw the transformation of identity to be relevant in the process of recovery. Ten of the studies viewed personal meaning of recovery as essential for understanding the recovery process.

Table 2
Thematic Classification of Publications, Number in Category.

Theme	Number of studies in each category
Medication: the importance of in recovery	8
Relationship with self and social world	5
Identity transformation	6
Personal meaning of recovery	10

Table 3
 CASP TOOL: 10 questions to help make sense of Qualitative research (Ratings: Strong = 8–10; Moderate = 5–7; Weak = 1–4)

Publication	1) Clear statement of aims?	2) Qualitative methodology appropriate?	3) Research design appropriate for aims?	4) Recruitment strategy appropriate for aims	5) Data collection addresses research issue?	6) Relationship between researcher and respondents considered?	7) Ethical considerations accounted for?	8) Rigorous data analysis?	9) Clear statement of findings?	10) Resee is vali
De Jager, et al, (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Gray & Deane, (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hargreaves, et al, (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lee, et al, (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ngubane, et al, (2019)	Yes	Yes	Yes	yes	Yes	Yes	Yes	Yes	Yes	Yes
Nowak, et al, (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Peter & Jungbauer, 2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sangeorzan, et al, (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Sumskis, et al, (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tuffour, (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Williams, et al, (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

3.3 Medication

There were eight studies that reported on differing aspects of medication. According to de Jager et al. (2016) the role of medication in the recovery process was seen as an important contributor to recovery. Medication facilitated recovery processes such as participation in the labour market. Gray and Deane (2016) found their respondents talking about the positive role for medication as it reduced psychotic symptoms, which reduced distress. Hargreave et al. (2017) saw some individuals report that medication coupled with physical activity acted as a coping mechanism toward the bad chemicals they believed medication released into their body. Lee et al. (2020) found their respondents in the process of recovery without ongoing medication use. Ngubane et al. (2019) identified that medication was beneficial in the process of recovery but only if other supports were also available. In the Nowak et al. (2017) study, participants believed that medication had to be carefully managed to be of benefit. Appropriate medication was important for recovery. It was also reported that medication for schizophrenia does not prevent relapse. Sumskis et al. (2017) suggested that medication is the cornerstone of treatment for schizophrenia. They also proposed that side effects are the major challenge for those with schizophrenia. Efficacy of different medication has been found to be similar but individual responses to medication may vary. It was reported that many in their study refused to take medication due to side effects. Lastly, Tuffour (2020) suggested that the role of religion was more important than medication for some of their respondents in the process of recovery.

3.4 Relationship with self and the social world.

Some of the respondents in the de Jager et al. (2016) study described how when the symptoms of schizophrenia were most severe the needs of the body were neglected, which made it impossible to participate in physical activity. For them it was as if the mind, self, and body were seen as separate entities, where the body did not feel as though it belonged to them, and they were completely absorbed in their mental processes. Others reported that their auditory hallucinations became an integral part of themselves. A positive sense of self was critical for recovery according to de Jager et al. (2016). According to Lee et al. (2020) other internal recovery processes included changes in how respondents viewed themselves as integrated with their mental health concerns. For example, some respondents recovered their self and perceived themselves to be a whole person, not a diagnosis. Caring for self was important for the respondents in the work of Lee et al. (2020), and exercise was seen as being extremely helpful. A sense of estrangement from the self was common for most respondents in their study. Ngubane et al. (2019) found that some of their respondents discussed how schizophrenia brought about changes to self. These included uncontrollable, dehumanizing and / or risky behaviour. As reported in this study, a motivating factor in the recovery process for these participants was to regain a sense of self which helped them to go beyond the limitations of schizophrenia to become the best they could for self and significant others. These others were also important for the subjects of the Ngubane et al. (2019) study as families and significant others played a significant role by providing emotional and financial support. A positive effect on self was experienced when some respondents were accepted socially and able to contribute to their family and community. Giving back was viewed as important in the recovery process.

Leading on from the recommendations of the respondents in their study Nowak et al. (2017) emphasized that recovery goes beyond the reduction of symptoms. They argue that it is of equal importance that the process of recovery be about finding meaning and purpose in life, along with respondent self-management, physical and mental health. These considerations can foster the development of relationships with others. Relationships with others creates a sense of belonging according to Sangeorzan et al. (2019), where this was evident in their study of respondents creating and publicly sharing mental health videos (vlogging) about the lived experience of schizophrenia. This study provided the first empirical evidence that engaging in the act of vlogging about mental illness can benefit and encourage recovery in people with serious mental illness (Sangeorzan et al. 2019). Importantly, vlogging is more common an experience for individuals without a mental illness (Sangeorzan et al. 2019). This being the case the impact of YouTube on the serious mental illness (SMI) population is a breakthrough. What was found was that vlogging facilitated an environment where those with schizophrenia uploading videos about their condition connect with viewers with similar illnesses and this validates the experience of mental illness, reducing feelings of loneliness, and reinforces a sense of normalcy (Sangeorzan et al. 2019).

3.5 Identity Transformation

The de Jager et al. (2016) study found their respondents moving beyond developing a positive sense of self to describe an essential transformation in identity because of becoming unwell and experiencing auditory hallucinations. This 'illness identity' was seen as a positive for some respondents. In the Hargreaves, Lucock and Rodriguez (2017) study some participants reported that exercise training in a gymnasium enhanced recovery by rebuilding identity. The transformation was from one of being ill to one that saw participants identify as a sports person. Other participants in their study displayed substantial behaviour change where reverting back to the types of training/physical activity respondents did before they endured schizophrenia (Hargreaves et al. 2017). Respondents in the Lee et al. (2020) research discussed the importance of finding social roles as a facilitating factor in their recovery process. The transformation was experienced in shifting from being seen as a patient with schizophrenia to identifying as a recovered person. It was reported by one participant for example that the role they moved towards was that of an active citizen, as someone who is contributing/participating in the social world. Nowak et al. (2017) discovered that their respondents referred identity transformation to several processes. Personal growth, developing a positive self-identity, acceptance of their schizophrenia, developing self-esteem and self-empowerment and stigma-management. Again, the transformation is one of the individual's identities being formed through drawing on their personal resources. Identity transformed from being ill to identifying as being recovered. Peter and Jungbauer (2019) found that notions surrounding identity and loss of identity were very present. Re-authoring/transforming identity was important for their respondents. The diagnosis of schizophrenia was seen to lead respondents to redefine their selves by creating new perspectives. The illness was viewed as a mere part of the self, not the centre of self. This was seen as a pivotal task for those in the study who were diagnosed with schizophrenia (Peter and Jungbauer, 2019).

3.6 Personal Meaning of Recovery

There were differing connotations regarding what recovery means for those individuals with schizophrenia. For respondents in the de Jager et al. (2016) study, being bold about what they had achieved through the process of recovery was significant – this included 'being strong' and rejecting stigma. In the Hargreaves et al. (2017) research it was shown that controlling symptoms of schizophrenia through physical activity was very meaningful for the respondents. Lee et al. (2020) found that for some in their study recovery did not mean the absence of symptoms but instead a different relationship with their symptoms. Some experienced their auditory hallucinations as being meaningful or interpretable. While others in the Ngubane et al. (2019) research defined the meaning of recovery as 'feeling better.' Nowak et al. (2017) found in common with the de Jager et al. (2016) that respondents not stigmatising themselves, not being identified as their illness, and viewing themselves as people with worth because they had survived schizophrenia was extremely meaningful. In addition, like many respondents in the preceding studies the meaning of recovery for those in the Peter and Jungbauer (2019) study was how to be able to cope with stigma. Specifically, how to cope with labels. Sangeorzan et al. (2019) indicated in their study that giving people control of the understanding of what their recovery process meant to them was a fundamental requirement for recovery. This was in the context of video logging about their experience of schizophrenia. Respondents found meaning in their recovery was aligned with what they could do for others undergoing the same lived experience. Meaningful recovery was characterised by having resilience, the attitude of striving to overcome the severe adversity caused by schizophrenia, for the respondents in the Sumskis et al. (2017) study. For those in the Tuffour (2020) research, recovery gained meaningfulness from being close to God. Being without God meant no recovery at all for the subjects of the study. Williams et al. (2018) discussed with participants what recovery was and what it meant. This included the concepts of "getting back to normal," "being positive" and "having good thoughts."

3.7 Assessment of Methodological Quality

All studies were assessed against the CASP tool (Table 2) against criteria aimed at evaluating the quality and reliability of the research. The assessment of the 11 qualitative research studies indicated consistently high quality. The "strong" results were achieved by having a score of between eight and ten "yes" scores, respectively. All 11 studies were strong across all criteria of the CASP tool. Ten of the included studies scored 10 (de Jager et al. 2016; Gray and Deane 2016; Hargreaves et al. 2017; Lee et al. 2020; Ngubane et al. 2019; Nowak et al. 2017; Peter and Jungbauer 2018; Sunskis et al. 2017; Tuffour 2020; Williams et al. 2018), with one scoring nine (Sangeorzan et al. 2019). There was one study that did not meet the criteria- "relationships between researcher and respondents"- but this was expected as the data collected by Sangeorzan et al. (2019) was limited as regards depth of content by the inability to ask follow-up questions. The study aimed to investigate the experiences of respondents with self-identified SMIs (Serious Mental Illness) who video log about their SMI on YouTube. CASP qualitative information regarding how those with schizophrenia experience the process of recovery making their findings meaningful in this context and purposeful as reliable and well formulated sources for analysis.

4 Discussion

When considering the themes that emerged from the analysis of the studies under review in the context of individual studies and the stories and experiences of participants reported in the studies, it became apparent that there is an over-arching, or meta-theme that is identified with recovery by the 86 respondents

diagnosed with schizophrenia. After reduction from 35 initial themes, four descriptive themes were identified that were expressed from a remarkably consistent perspective. This was expressed by respondents describing meaningful recovery in terms of connections made of several types between study subjects, other people – including personal and professional contacts, societal structures and institutions and the manifestations of their own internal processes, physical and mental experiences. The interpretative construct 'Connection' is identified as this meta-theme. What recovery meant for those with schizophrenia was that success or failure depended on the type and quality of connections they were able to make. The core of lived experience for those with schizophrenia in the recovery process was that connection gave meaning to the recovery process. By way of interpretation, medication allowed the person to connect with their self (de Jager et al. 2016; Gray and Deane 2016; Hargreaves et al. 2017; Lee et al. 2020). This enabled the person to connect with others more successfully and participate/connect in the social world (de Jager et al. 2016; Ngubane et al. 2019; Nowak et al. 2017). This in turn leads to a shift in identity from being ill and isolated and transformation of identity into active citizens (Hargreaves et al. 2017; Lee et al. 2020; Peter and Jungbauer 2019). This enabled the person with schizophrenia to give meaning to their recovery process. Respondents were in recovery and not in remission (Nowak et al. 2017; Sangeorzan et al. 2019). Connection acted as the mediator between the medical approach and lived experience models of recovery. They are not presented as challenges to each other but as complementary. The self of the person with schizophrenia is shown to be of equal importance to their use of medication in the recovery process (Deegan 1988). Recovery is identified by respondents as being about who they are and not about how sane or how normal they could be. Respondents find meaning and purpose in life is enabled by connection. Connection aids the recovery process and gives value to the uniqueness of those with schizophrenia (Anthony 1993). The strength of the findings was apparent as the current literature was supported by the results of the reviewed literature. The answer to the research question; how do those with schizophrenia experience the process of recovery, is discovered by the respondents of the reviewed literature as a varied, complex, and uniquely subjective experience.

5 Limitations

The risk of the review being seen to suffer selection bias and excluding any relevant studies was reduced due to strong inclusion/exclusion criteria as well as secondary cross-checking during data extraction and analysis. Further, included studies were subjected to the CASP tool for assessing applicability, reliability, and validity and cross-checked by both the secondary author and an independent academic reviewer. As a review focused by necessity on qualitative studies there may be potential for future work to focus on quantitative assessment of the reported experiences of individuals identifying as having schizophrenia in recovery.

6 Conclusion

One of the most important findings in the current literature is that the recovery process is uniquely subjective. This was mirrored by the respondents in the reviewed literature. The current state of the reviewed literature is extremely supportive of the lived experience of recovery processes for those with schizophrenia. Recovery is a process that is exciting and challenges assumptions about normality (Bejerholm and Roe 2018). Connecting with self and the social world sees those with schizophrenia understand that recovery is possible (Anthony 1993) and their new-found identity is not one of being in remission but of being in recovery. One future area for study in the light of this concept is that of schizophrenia being a disorder of the self. The reviewed literature supported the theoretical approach that the person with schizophrenia needed to regain their lost self before taking further steps in the recovery process. Future research of schizophrenia as a self-disorder being phenomenologically designed would further highlight the necessity of this for the recovery process. This would link to existing knowledge in two areas: recovery as lived experience and symptomatic recovery. Recovery is not viewed as an end. It is not an achievement. Rather, as de Wet et al. (2015) argue, it was a way of living and a constant choice that those with schizophrenia must make in pursuit of a healthy, meaningful, and 'connected' existence.

Declarations

Statements and Declarations

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Figures

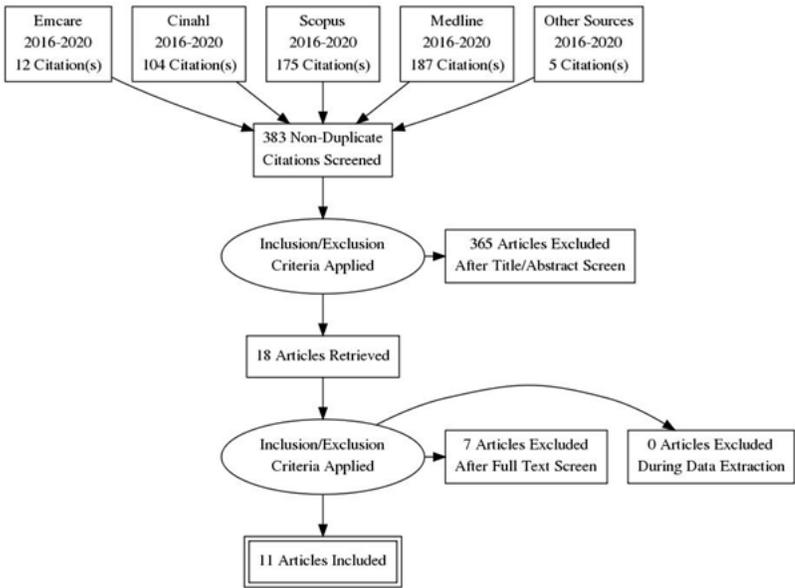


Figure 1

PRISMA Diagram of the screening and filtering process.