

**Recovery in psychosis from a service user perspective: A thematic
synthesis of current qualitative evidence**

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Abstract

There is a growing number of qualitative accounts regarding recovery from psychosis from a service user perspective. The aim of this study was to conduct a systematic review of these qualitative accounts. A thematic synthesis was utilised to synthesise and analyse seventeen studies included in the review. Studies were included if they used a qualitative methodology to explore service users' experiences of recovery from psychosis as a primary research question. All included studies were subjected to a quality assessment. The analysis outlined three subordinate themes: the recovery process, facilitators of recovery (e.g. faith and spirituality, personal agency and hope), and barriers to recovery (e.g. stigma and discrimination, negative effects of mental health services and medication). Recovery is an idiosyncratic process but includes key components which are important to people who experience psychosis. These should be explored within clinical practice.

Key words: Recovery, psychosis, thematic synthesis, systematic review,

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Introduction

Recovery is routinely considered within the mental health care of people who experience psychosis. Mental health practitioners typically describe recovery in psychosis as an absence of symptoms, a reduction in hospitalisation and relapse rates (1). In clinical research trials which form the evidence base for medical and psychological treatments, recovery is conceptualised as a quantitative improvement in psychotic symptoms and functioning. However, in direct contrast, service users describe recovery as an idiosyncratic process, not an outcome, encompassing hope, rebuilding self and rebuilding life (2). Service users have defined recovery as ‘the establishment of a fulfilling meaningful life and a positive sense of identity founded on hopefulness and self-determination’ p.588 (3). Furthermore, service users state that recovery can occur without the full alleviation of psychotic symptoms (4).

There is growing evidence comprising qualitative accounts of the conceptualisation recovery in psychosis from a service user perspective. They highlight important factors such as the role of hope, alleviating public and internalised stigma, empowerment, personal goals and social support (1, 5-7). Mental health services and policy makers had attempted to include such components into their conceptualisation of recovery (8-10). Although this has led to increased hopefulness in mental health services regarding recovery in psychosis, there continues to be apprehension about how to integrate service user perspectives meaningfully into clinical practice. This is potentially a consequence of recovery being described as an individualised process leaving clinicians with uncertainty in how to implement a recovery approach (1). Synthesis of service user perspective of recovery in psychosis is required to overcome this continued uncertainty regarding the implementation of recovery in psychosis.

The only review conducted specifically examining recovery in psychosis identified four key processes of recovery: finding hope, reestablishment of identity, finding meaning in life and taking responsibility; and five distinct stages: denial and hopelessness, awareness, preparation, rebuilding and growth (3). However, this review is outdated and also lacked methodological rigour now expected from qualitative reviews. A comprehensive systematic narrative review was conducted by Leamy, Bird (11) who conceptualised recovery through examination of theoretical frameworks and service user perspectives. Their review identified thirteen characteristics of the recovery journey such as recovery being a gradual and non-linear process, and five distinct processes including connectedness, hope, identity and empowerment. However, this was not psychosis specific. Service users with psychosis arguably have different recovery needs compared to other mental health diagnoses as they: have the lowest rates of recovery (12), high rates of public stigma (13), high levels

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of trauma (14), higher rates of self-harm and suicidality (15), and reduced social networks (16). It would be helpful to understand these further.

It is acknowledged that the majority of recovery literature is gained from qualitative accounts (11), therefore synthesising these accounts would provide an important overview of the largest area of the recovery evidence base. Systematic reviews of qualitative literature are increasingly becoming acknowledged as an important method to contribute to the evidence base of a specific field (17). Therefore, the aim of this study was to conduct a systematic thematic synthesis of the recovery from psychosis qualitative literature.

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Method

Ethical considerations

This study did not require ethical approval as it only reviewed studies which were published and had sought individual ethical approval. No conflicts of interests arose when undertaking the review.

Search criteria and procedures

The review included studies where (a) the primary aim was exploring recovery from a service user perspective, i.e. examining their subjective opinions about recovery (b) included participants where more than half (>50%) met criteria for (i) a schizophrenia-spectrum diagnoses (schizophrenia, and schizophreniform disorder, schizoaffective disorder, delusional disorder, psychotic disorder not otherwise specified defined by any criteria) or (ii) threshold for early intervention services (to allow for diagnostic uncertainty) (c) participants were aged 14-65 (d) published in a peer reviewed journal, (e) in English language (f) used semi-structured interviews or focus groups (to allow for examination of methodological rigor). Studies were excluded if they were examining recovery in those with organic psychosis, post-partum psychosis or substance misuse disorders.

The search was conducted in June 2015 by author LW. MedLine, PsychInfo and Embase databases were used to search for studies published between 1946 and June 2015. These search engines were chosen to ensure extraction across both medical and psychological journals. Combinations of the following keywords were used in the search: recovery AND psychosis OR hallucination* OR delusion* OR schizo* AND qualitative OR interview* OR focus group*. Review papers identified in the search were also extracted and their reference lists were examined.

Methodological quality and risk of bias of included studies.

Methodological quality was assessed using guidance outlined by Thomas, Sutcliffe (18) in reviewing qualitative research. Included studies were judged against twelve criteria which broadly pertained to the quality of reporting, strategies for establishing reliability and validity in data collection and analysis, and the extent to which findings were rooted within a service user perspective. Studies were rated individually as having made no attempt, some attempt or a good attempt against these criteria. Quality assessments were carried out by the first author (LW) and cross checked by the second (SA).

Analysis

Analysis was guided by the thematic synthesis of qualitative research approach described by Thomas and Harden (2008). Thematic synthesis is a method of analysis which synthesises findings from

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qualitative studies using thematic analysis. It uses the results of qualitative studies as data which are coded and examined for analytical themes. The full results section of each included paper were included in the analysis and used as data which included both service user quotes and author interpretations. The first stage of the analysis, conducted by author LW, involved reading and re-reading through each research paper until a good level of familiarity was achieved. Each paper's results section was individually coded line-by-line and 148 initial themes were identified. In the second stage, conducted by both authors, these codes were then grouped together to form analytical superordinate and subordinate themes. These analytical themes reflected important recovery components and were decided upon by considering the frequency and pertinence of codes.

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Results

Study Selection

The search produced 1553 results and is outlined in figure 1. Removal of duplicates left 1081 studies. Study titles and abstracts were examined by author LW. Twenty nine studies were screened at full text and seventeen were included in the final analysis. All included studies can be found in table 1.

[INSERT FIGURE 1 HERE]

[INSERT TABLE 1 HERE]

Assessment of bias

As stated, all studies were assessed against Thomas, Sutcliffe (18) criteria of methodological quality (table 2). All studies met the quality of reporting criteria (first five items). All studies met the reliability of data collection methods criteria as they all made some attempt at increasing reliability of data collection such as having an interview/focus group protocol, audio recording and transcribing data. Two studies (6, 19) did not meet validity of data collection criteria as they did not adequately describe how they generated their interview and focus groups schedules. All studies except two (19, 20) made some attempt, through procedures such as triangulation and cross checking, to ensure their data analysis was reliable. All studies described validity procedures for data analysis except Forchuck, Jewell (19) who therefore could not score on this item. All studies met the first two criteria assessing the degree of which data analysis was embedded within service user perspectives. Only five studies involved service users within their data analysis; three studies involved those with lived experiences within their research team (2, 21, 22) and two adapted their data collection methods in light of service user feedback (23-25). Overall, all studies were deemed of acceptable quality and included in subsequent analysis.

Thematic Synthesis

Analysis of the seventeen (n=17) studies resulted in the development of three superordinate themes, the recovery process, facilitators of recovery and barriers to recovery (table 3). ‘The recovery process’ outlines four distinct stages of recovery, ‘facilitators of recovery’ highlighted important factors which can support the recovery process and ‘barriers to recovery’ outlined factors which can hinder the recovery process. These themes included a number of subthemes which will be described below using verbatim quotes.

The Recovery Process

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The analysis confirmed that recovery was a long-term process of change where improvements, stability, and relapse were possible. The recovery process was idiosyncratic and priorities would shift throughout.

“Seven participants made slow, steady progress, three fluctuated, and one declined. Although many of those who continued ‘struggling’ did make some progress in recovery, it tended to be extremely slow with ups and downs as well as plateau periods used for integration and consolidation of gains, healing, confidence building, and re-energizing of the self”. Author, pp.334 (20).

The recovery process included four subordinate themes which represented specific stages of the recovery process. These included the person prior to psychosis, experiences of psychosis, reconciliation, and rebuilding self and life.

Person prior to psychosis

The person prior to psychosis theme reflected the first stage in the recovery process. It described a person’s identity and life experiences prior to the onset of psychosis. Some studies acknowledged this as an explicit stage preceding the recovery process within their individual analyses. The remaining studies referred to a past self or past trauma and the importance of reconciling these as part of the recovery process.

“The phase captures the lives of participants prior to the illness. Specifically the nature of participants’ lives, their identities and aspects of their lifestyle are featured” Author p.246.(23)

Pre-psychosis stress and trauma

All studies explicitly stated the importance of reconciling past stress with a particular focus on trauma. Studies acknowledged that the majority of participants had some experience of trauma or abuse which they needed to come to terms with. This reconciliation was most likely to happen by opening up and discussing the past, particularly through psychological therapy.

“There is also a point that I have discovered in the past few months having run through my childhood stuff in counselling and sorted out long-standing things that I have been meaning to sort out. I’m now saying I can now step away from this and get on with other things” Participant p.57 (2)

Episode of psychosis

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The next stage of the recovery process was experiencing an episode of psychosis and how people made sense of this. This represented a first episode of psychosis or a subsequent episode. A first episode of psychosis was described as most confusing and distressing. Each episode of psychosis was appraised differently by each person, some viewed it positively but the majority viewed it negatively.

“Feelings of disappointment and despair resulting from the impossibility of dealing with their life situation appeared to worsen a sense of impotence vis-à-vis their problems”. Author p.478 (24).

A subtheme identified in a handful of studies was that a descent into psychosis could also be a positive experience (22, 25).

“...and I just felt really calm all of the sudden and I heard a voice in my head that said: “Terri you have to love unconditionally” And that was it. It wasn’t even my voice. And I just felt really....spiritual” Participant. P.625 (25).

Loss, uncertainty and fear

All studies outlined that an episode of psychosis is often accompanied with a sense of loss, uncertainty and fear. Studies stated that the new and unusual experiences would cause confusion and a significant need to make sense of what was happening.

“I really lost myself...I’m just trying to get back to me” Participant, p.4 (26).

Integration of psychosis

Integration of psychosis referred to the third stage of recovery and involved personal ways of coming to terms with experiencing a psychotic episode. Reconciliation was more than just coping with experiences of psychosis it involved integrating such experiences into one’s identity and making sense of life following an episode. Acceptance was integral to this.

“The experience of reconciling included processes of differentiating between the illness and the self, forming a coherent explanation and reconciling the personal meaning of the experience and implications for the future”. Author p.1072 (27).

An important part of reconciliation was making sense and meaning of the psychosis experience. Learning from the episode of psychosis was also outlined as important.

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“The psychotic episode was understood by many participants as an opportunity to change. In most reports, this change was seen as the ‘positive side’ of the psychosis. This change, according to the subjects, brought learning and maturity” Author, p. 479 (24).

Rebuilding self and life

Rebuilding self and life represented the last stage of the recovery process. It was the stage which reflected long-term goals and is most complex. This stage included important recovery outcomes that suggest recovery has occurred. It incorporated a variety psychological and social factors which are personal in nature. A number of examples included rebuilding confidence, gaining employment, and taking up new hobbies and activities. This theme had the most codes contributing to it out of all the recovery stages indicating its importance.

“I’m almost fully recovered cos I’m pretty much doing the stuff I want to be doing... my family tells me that I’m now the same as before, such as my personality. I’m talking as much as I used to. My behaviour is back to the way I was, and I’m smiling again” Participant, p.583 (6).

Establishing meaningful social activities was identified in all studies and was important in facilitating recovery and developing a positive self-image. These factors were recognised across the studies to contribute to the process of recovery. Meaningful activities built confidence and self-esteem and increased social connection.

“Over time, individuals gradually increased their sense of self, gained a sense of personal power, built connections with others, developed new meaning and purpose in their lives, and established themselves as contributing members of their communities”. Author, p.334 (20).

Facilitators of recovery

Facilitators of recovery were important factors which supported the recovery process. Depending on the individual, some were more important than others. They were used and understood in a personal way. For example, some people may prioritise support from friends and having hope whereas some others may prioritise family and spirituality.

Social support

Social network support was essential for service users in all studies and was the primary factor which facilitated the recovery process. Social network support could be accessed through many social

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groups, e.g. family, work colleagues, friends, however family was cited as most important. Consistency, practical and emotional support within the social network were particularly important.

“Participants consistently identified specific family members, peers, friends, and professionals who facilitated their recovery process by offering hope, encouragement, and opportunities”. Authors, p.333 (20).

Faith and spirituality

Faith and spirituality was identified as an important facilitator of recovery by over three-quarters of included studies. It offered two distinct functions, a way of making sense or meaning of the psychosis experience and also comfort and support.

“I believe it (psychosis) gave me a faith in a higher power; it gave me comfort that I’m never alone completely, I always have that connection. I may be alone in my body, but I’m we’re all connected to a higher power that’s within us” participant p.627 (25)

Personal agency and hope

Service users described the recovery process commencing once they took ownership of their experiences through gaining personal agency and hope. The studies referred to a transition from a helplessness and fearful role towards taking ownership. Ownership would occur at different stages of recovery with some people taking ownership very early on in the process and others taking longer. It was at the point of ownership that participants felt empowered and believed that they could recover. This involved having realistic and accurate awareness of one’s strengths and abilities to progress to recovery, and being able to take pragmatic and practical steps towards managing their difficulties.

“Research suggests that empowerment is central to the recovery process and people who experience psychosis employ a variety of strategies to empower themselves. They seek knowledge about their experience of psychosis that enables them to have more control... They seek out activities that increase their self-esteem which, in turn, enables them to assert their needs better”. Authors, p.58 (2).

Environmental resources

Environmental resources were identified by over half of studies as an important facilitator of recovery. Meeting one’s basic needs had a central role to recovery as service users described the importance having a secure base of stability where one could feel safe in order to focus on their mental health recovery.

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“On the most basic level, people needed concrete resources such as food, clothing, shelter, and access to supportive therapeutic environments as well as medical, substance abuse, and psychiatric treatment”. Author, p.333 (20).

“Recovery... well getting on the path where I am now, being able to go back to work, hold a job down, carry on with normal things”. Participant, p.57 (2).

Positive support and holistic care from services

Positive support and holistic care from mental health services or non-statutory organisations was identified as imperative. Emphasis was placed on person-centred care which would tolerate uncertainty and allow the service users to make their own decisions around their mental health care. The importance of implementing treatments other than medication was recognised in order to manage one’s mental health problem.

“Those interviewed recognised the need for a more collaborative approach, greater continuity in care, protection from harm by professionals, wider choice of treatment, more emphasis and guidance on recovery, alternatives to the medical model and more user involvement” Author, p.58 (2).

Professionals adopting a hopeful and optimistic attitude towards the service user’s recovery positively influenced one’s belief in their ability to work towards recovery which in itself facilitated recovery.

"Support all the way round... money, partners [...] health professionals... You need positive people in your profession. You don't need people who say, 'She'll never recover. She's for the scrapheap, she'll never work again, she's on medication for the rest of her life'". Participant, p.191 (22).

Barriers to recovery

A number of barriers to recovery were identified by included studies. These themes had less contributing codes than all other themes but were spoken about with considerable passion. Stigma, discrimination and negative impacts of mental health services and medication were discussed most frequently by participants of included studies.

Stigma and discrimination

Stigma and discrimination was a significant concern for people who experienced psychosis. Experiences of stigma came in many forms but stigma was most painful when it was from people who participants cared about. Stigma and discrimination had two main impacts, by limiting opportunities

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and chances to move forward with recovery, e.g. gaining employment, and causing personal distress by internalising stigma.

“He stigmatises me... he doesn’t give himself a chance to realise that I’m really in remission...he thinks that once you’re mentally ill, you’re always mentally ill, and that’s not the case...” Participant, p.47 (7).

Social deprivation

Participants within individual studies spoke passionately about social exclusion from community groups, lack of income, poor quality housing and lack of opportunity as a result of experiencing psychosis.

“You just resign yourself to the fact that there’s never enough money”...”Participants’ quality of life was almost entirely dependent on the meagre resources available through entitlement and benefits programs” Participant and Author p. 332 (20)

Substance misuse

Substance misuse was described as worsening experiences of psychosis developing into a primary issues overtaking psychosis and preventing the ability to achieve the final stage of recovery of rebuilding self and life. Although this was not be a problem for all people who experience psychosis, when it was it had significant detrimental effects.

“Seven of the 12 subjects were struggling with a substance abuse disorder in addition to schizophrenia. During periods of active substance use, even when psychiatric symptoms were present, the substance abuse disorder became the predominant disabling condition” Author, p. 332, (20)

Negative impacts of mental health services and medication.

Participants described negative experiences of mental health services and medication which significantly hindered their recovery and prevented engagement with services. Negative experiences of mental health services were most often described within the context of an inpatient admission.

“Two male nurses can’t cope...you can say, ‘No, I don’t want an injection’ [...] three nurses is the worst. I call it ‘a gathering of three’. Each one would hold an arm and the other would slap and punch you until you agreed to be injected” Participant, p.188 (22)

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Negative impacts of medication usually referred to the extrapyridamal side effects from taking anti-psychotic medication.

“The majority of participants spoke of feeling stupified, numb, and slowed down, of being unable to interact in a normal fashion or undertaken even modest activities, most wanting to sleep or lie down”

Author p.73 (28)

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Discussion

The aim of this study was to conduct a systematic review of qualitative literature examining service users' experiences of recovery from psychosis using thematic synthesis. A total of seventeen studies were included in the study which examined service users' subjective experiences of recovery from psychosis. Three definitive themes were identified, the recovery process, facilitators of recovery and barriers to recovery.

Supporting previous literature (2, 11), recovery was conceptualised as a fluctuating process without a definitive endpoint in all studies included in this review. The synthesis identified four distinct phases which provided understanding about the key components of the recovery from psychosis process. Importantly, a number of psychosis specific factors were emphasised such as overcoming past trauma and stigma. A variety of psychosocial factors were identified which illustrated the continued need for services to provide support and treatment which does not primarily focus on symptom removal. Although, alleviation of psychosis was identified as important to the recovery process supporting previous literature (21), it only contributed a small proportion of what was important. Clinical treatments and therapies continue to only be considered effective if they alleviate symptoms of psychosis (1). This review illustrates that this needs to be broadened and encompass recovery factors. More recent outcome measures have been developed to reflect service user recovery priorities (29), and should be encompassed into future clinical trials and clinical practice.

The recovery process superordinate theme also identified the importance of understanding the recovery process, particularly past experiences and identity, from an individual perspective. This could be achieved through the development of a detailed recovery-focused psychological formulation to inform a service user's mental health care. A formulation is the development and understanding of a person's difficulties from a psychological perspective (30). A number of NHS trusts have already begun integrating Cognitive Behavioural Therapy (CBT) informed psychological formulations into care plans for all service users (31). Doing so improves optimism, reduces patient-blame and increases staff confidence in their ability to support a person with psychosis. (32).

The facilitators of recovery theme identified five distinct areas which mental health services should support service users to develop in order to promote recovery. In particular, faith and spirituality were identified as important factors which are not prioritised enough by mental health services. A collaborative exploration of the spiritual dimensions of a service users experiences is important in supporting recovery (33). Furthermore, the theme positive support and holistic care from services identified the importance of non-statutory services. Recent recommendations by service users

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advocate for an integrated care approach encompassing other organisations such as the spiritual crisis network and the hearing voices network (34).

The barriers to recovery highlighted in this review are of particular interest. Given all the recent research examining recovery, less is known about what hinders recovery. Stigma and discrimination and negative impacts of mental health services were identified as most prominent barriers. Stigma is an ongoing priority outlined by the most recent government manifesto (35) and large scale campaigns are aiming to tackle stigma at a national level (36). However, there is much more that mental health services can be doing to support individuals suffering from the impacts of stigma. Stigma has been shown to cause anxiety, depression and impede recovery (37). Mental health services could offer support groups and interventions which can prevent these consequences. The negative impacts of mental health services are something which needs to be seriously considered and addressed. Participants spoke passionately about this within individual studies. Treatment from mental health services, particularly an inpatient admission, have been found to retraumatise people who experience psychosis (38). Further exploration of service users' view on how to improve services is vital.

The theme of social network support identified key personal groups which are important throughout the recovery process; family, friends and peers. Caring and understanding from meaningful social relationships were of particular importance. Service users require social support where they feel they feel valued and able to be themselves. It is essential that service users' social network is supported so they can develop an understanding about psychosis and can discuss their concerns openly. Having meaningful input from social networks is likely to sustain long-term recovery process. The recent NICE guidelines for schizophrenia emphasise the importance of family and carer input (39).

Strengths and Limitations

This review is the first of its kind aiming to synthesise the psychosis-specific recovery literature using systematic review methodology. It included two studies undertaken in collaboration with service users, which added to the richness of the data extracted. Service user voices are not prioritised (40) and it is essential their perspectives are integrated meaningfully into a given evidence base. By completing a systematic review of the qualitative literature this study was able to synthesise and collate service user views in a reliable manner.

A limitation was the integration of qualitative literature which is criticised for its small sample size and lack of generalizability. Moreover, the review included people at different stages of recovery and also people where their recovery progress was unknown. However, a large sample of service users was considered in this review which improves reliability. Another limitation was the exclusion of the

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grey literature. There is a wealth of information written by service users about the recovery process, which was not included. Nonetheless, it was important to incorporate methodological rigor and thus include studies which would meet the review's quality criteria.

In conclusion, recovery is as an idiosyncratic process with important facilitators and barriers. The recovery process will fluctuate throughout the recovery process and it is important they are reviewed regularly in collaboration with the service user.

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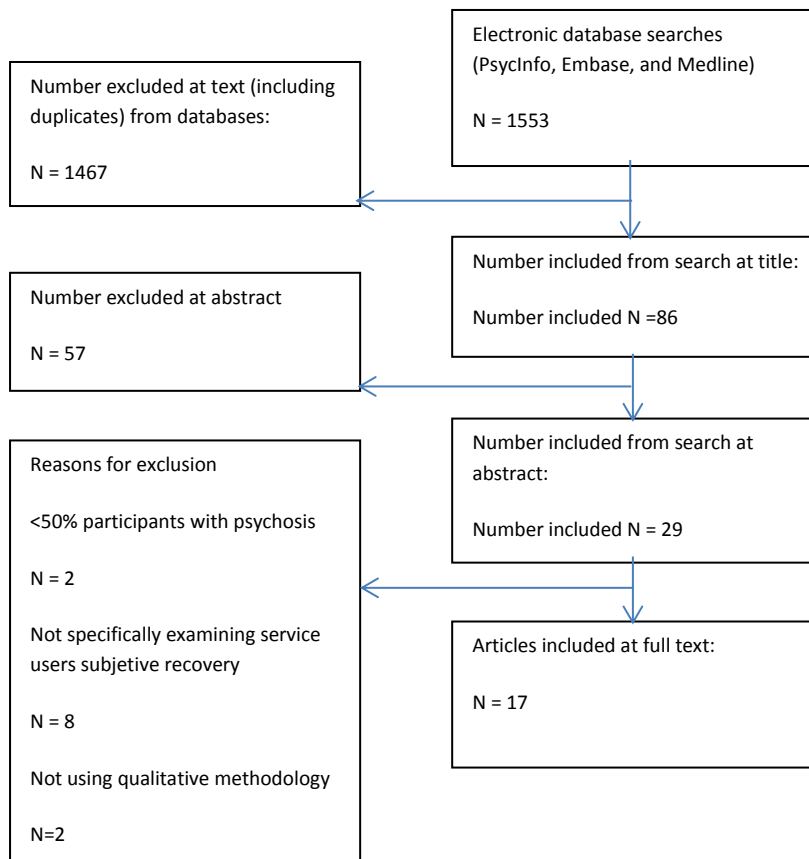
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Figure 1 –Search strategy



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Table 1 – Summary of papers included in the analysis

| | Authors | Participants included | Service context | Methods and analysis | Demographics | Perceived Recovery progress |
|---|-----------------------------|------------------------------|--|--|---|--|
| 1 | Spaniol, Wewiorski (20) | Service Users, N=12 | Recruited from a vocational training research study. USA. | Semi-structured interviews every 4-8 months for 4 years. Average of 7 interviews per participant. Thematic analysis. | Male 6/12, X Age 40.75(SD:5.88) Black 7/12, White 4/12, Asian 1/12 Single 9/12, Schizophrenia 5/12, Schizoaffective 5/12, Paranoid Schizophrenia 2/12 | 2/12 made no recovery throughout the study, 10/12 made some improvement |
| 2 | Forchuck, Jewell (19) | Service users N=10 | Participants from a clinical service were interviewed before or during medical treatment for a year. Canada. | Each participant completed 9 semi-structured interviews. Ethnographic method for data analysis. | Male 5/7, Aged 26-51 White 10/10, Duration of psychosis 8-15 years | 9/10 inpatients at start of study, 4 recovered greatly, 6 to a degree, 2 minimal improvement |
| 3 | Tooth, Kalyanasundaram (28) | Service Users, N=57 | Purposively recruited participants from local newspaper. Australia. | Four part qualitative interview process and consultation of 2 focus groups. Thematic analysis | Males 43/57, X age at diagnosis 22yrs Illness duration 14yrs, Schizophrenia 57/57 | All participants identified themselves as recovered. |
| 4 | Thornhill, Clare (22) | Service Users, N=15 | Recruited through advertisement and word of mouth. UK. | Semi-structured interviews. Narrative analysis | Male 6/15, Age 30-70 Schizophrenia 7/15, schizoaffective 2/15, bipolar 4/15, psychotic episode 2/15, depressive episode 2/15, White 13/15, Asian 2/15 | Recovered or recovering from psychosis |
| 5 | Davidson and Roe (41) | Service Users, N=12 | Recruited internationally from clinical services. USA. | Semi-structured interviews, thematic analysis | Male 5/12, Age 29 – 55 Schizophrenia 9/12, Depression with psychosis 3/12, Single 11/12 | All participants were recovered or recovering from psychosis. |
| 6 | Pitt, Kilbride (2) | Service Users, N=7 | Purposive recruitment of community sample. UK. | Semi-structured interviews. Interpretative Phenomenological Analysis | Male 5/7, Aged 18-65 White 6/7, Mixed race=1/7 | N/K |
| 7 | Ng et al (2008) | Service | Recruited from a | Three hour focus group. | Male 4/8, Age 36 -43, Schizophrenia | N/K |

| | | | | | | |
|----|---------------------------|--|---|--|--|---------------------------------|
| 8 | Shea (7) | Users, N=8 Service Users, N=10, Partners, N=4 | community sample. Hong Kong. Recruited from a community sample. USA. | Thematic content analysis 19 Semi-structured interviews. Grounded theory | 6/8, Schizoaffective disorder, 2/8, Duration of illness 3- 22 years Male 5/10, Age 33-62 Schizophrenia 10/10 | N/K |
| 9 | Romano, McCay (23) | Service Users, N=10 | Recruited from a community sample. Canada. | Semi-structured interviews. Grounded theory | Males 5/10, Age X=23 White 4/10, Black 4/10, Asian 2/10 | Recovered from FEP |
| 10 | Wood, Price (21) | Service Users, N=8 | Purposive recruitment of community sample. UK. | Semi-structured interviews. Interpretative Phenomenological Analysis | Males 6/8, Age 24-35, 8/8 psychosis Early intervention 6/8, CMHT 2/8 | N/K |
| 11 | Nixon, Hagen (25) | Service Users, N=17 | Recruited through advertisement in community. Canada. | Narrative interviews. Thematic analysis. | 2/17, Age 25-64 | Recovered from psychosis |
| 12 | Lam, Pearson (6) | Service Users, N=6 | Opportunistically recruited from EIP service. Hong Kong. | Focus group. Content analysis | Male 3/6, Age 23-28, Paranoid Schizophrenia 4/6 | N/K |
| 13 | Eisenstadt, Monteiro (24) | Service Users, N=16 | Recruited from FEP programme. Brazil. | Semi-structured interview, narrative analysis. | Male 12/16, Age 15-29 Single 15/16, Paranoid Schizophrenia 8/16, Schizoaffective Disorder 3/16, Schizophreniform 2/16, Other 3/16 | N/K |
| 14 | Windell and Norman (42) | Service Users, N=30 | Recruited from EIP services. Australia. | Semi-structured interview. Thematic analysis | Male 23/30, X Age 25.87, Single 27/30 Schizophrenia 16/30, Schizoaffective 8/30, other 6/30 | N/K |
| 15 | Connell, Schweitzer (26) | Service Users, N=26 | Recruited from EIP services. Australia. | Semi-structured interview. Interpretative Phenomenological Analysis. | Male 20/26, X Age 21, Psychosis FEP 26/26 | At the first stages of recovery |

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|----|----------------------|---------------------|---|--|--|---|
| 16 | (4) | Service Users, N=7 | Recruited from larger a EIP study. South Africa | Semi-structured interview. Interpretative Phenomenological Analysis. | Male 4/7, Age 23-46, White 1/7, Black 6/7, Schizophrenia 5/7, Schizophreniform disorder 2/7. | N/K |
| 17 | Windell, Norman (27) | Service Users, N=30 | Recruited from EIP services. Canada. | Semi-structured interview. Interpretative Phenomenological Analysis. | Male 23/30, White 27/30, Asian 1/30, Black 1/30, Other 1/30, Schizophrenia 16/30, Schizoaffective 8/30, Psychosis 3/30, Drug-induced psychosis 2/30, bipolar 1/30. | 17/30 describe themselves as recovered. |

N/K = Not known, EIP = Early Intervention in Psychosis

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Table 2 – Assessment of bias of studies against Thomas and Harden Criteria

| Quality Criteria | | N making at least 'some attempt' |
|---|--|-------------------------------------|
| Quality of reporting | Aims and objectives were clearly reported | 17 |
| | Adequate description of the context of the study | 17 |
| | Adequate description of the sample | 17 |
| | Adequate description of data collection methods | 17 |
| | Adequate description of data analysis methods | 17 |
| Reliability and validity | Reliability of data collection methods | 17 |
| | Validity of data collection methods | 15 |
| | Reliability of data analysis methods | 15 |
| | Validity of the results of the data analysis | 16 |
| Findings rooted within service user perspective | Studies used appropriate data collection methods for service users to express views | 17 |
| | Studies used appropriate methods for ensuring the data analysis was grounded in the views of service users | 17 |
| | Studies involved service users in the design and conduct of the study | 5 |

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Table 3 – Recovery themes

| The Recovery Process | Facilitators of Recovery | Barriers to recovery |
|---|---|--|
| <p>Person to prior to psychosis Pre-psychosis stress and trauma</p> <p>Episode of psychosis Loss, uncertainty and fear</p> <p>Integration of psychosis Synthesis and acceptance</p> <p>Rebuilding self and life Encompassing psychosocial factors</p> | <ul style="list-style-type: none"> • Faith and spirituality • Social support • Personal agency and hope • Environmental resources • Positive support and holistic care from services | <ul style="list-style-type: none"> • Stigma and discrimination • Social deprivation and lack of opportunity • Substance misuse (drugs and alcohol) • Negative effects of mental health services and medication |

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