#### ORIGINAL ARTICLE



# Meaning of Recovery Among Persons with Schizophrenia: A Literature Review

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Received: 4 October 2017/Accepted: 9 November 2017/Published online: 23 April 2018 © Springer (India) Private Ltd., part of Springer Nature 2018

**Abstract** Since many years, the concept of recovery in mental illness has been discussed from different perspectives of the patient, family and mental health professionals. In the literature there are numerous definitions of what recovery means. A persistent theme in mental health recovery literature is that a concise definition of recovery is hard to determine. It is acknowledged that recovery means different things to different people, and that not every view of recovery will fit with every person's belief system. This article aims to identify the meaning of recovery in the published literature among persons with Schizophrenia.

**Keywords** Recovery · Schizophrenia · Literature review · Subjective meaning

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## Introduction

'Recovery', as used by mental health consumer advocates, differs from the commonly-held meaning of the return to a previous level of health and functioning after illness. Consumer-oriented definitions of recovery refer instead to changes in attitude to life and the illness, emphasizing the role of hope. They refer to the establishment of a meaningful and fulfilling life, a positive sense of identity and taking responsibility for one's own wellbeing [1–4].

Recovery can be defined as ".... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness..." [2]. Recovery-orientated approaches offer an alternative to clinical models of recovery traditionally focused on cure from disease and reduction in symptoms [5]. Recovery concerns a broader picture of living well with mental health issues. In recoveryfocused services, the professional listens to what each person thinks is important to their own recovery. Recovery is defined as a highly individualized process rather than an end-point; it involves the re-establishment of identity and regaining hope, meaning and autonomy despite the presence of recurring or persistent symptoms [6]. In recovery, symptomatic improvement is still important, and may well play a key role.



The most powerful evidence for recovery therefore lies in the narrative accounts of individuals rather than in changes in the severity of symptoms over time [7].

## Recovery in Schizophrenia

Several authors suggest that the services of people diagnosed with schizophrenia should be recoveryoriented rather than illness-oriented [6, 8, 9]. Recovery from schizophrenia includes not only symptom remission, but also hope, self-redefinition, having a meaningful life, and self-responsibility; therefore, a recovery-oriented mental health service is essential for people living with schizophrenia [1, 10]. How recovery from schizophrenia is envisioned is likely to vary greatly between individuals. Identifying the personal goals that are of most importance to each individual patient is critical [11]. Identifying consumers' goals and perceptions can help them to improve self-efficacy and to empower themselves. Being able to define their own recovery can help them to evaluate treatment outcome based on the criteria set by the patients themselves [12]. Reviewing the literature on subjective meaning of recovery will help us to understand, the common aspects in the meanings of recovery. This would also be helpful in developing recovery oriented research and interventions. With this background, the authors aimed to systematically review studies, which have explored the subjective meaning of recovery among persons Schizophrenia.

### **Materials and Methods**

The main aim is to identify the subjective meaning of recovery among persons with Schizophrenia in the published literature. Studies were selected and reviewed based on the predefined inclusion and exclusion criteria, as given below:

Inclusion Criteria	Exclusion Criteria
Quantitative or qualitative studies on subjective recovery	Studies explaining only clinical recovery from Schizophrenia
Published During 2006–2016	Various clinical trials pertaining to schizophrenia

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Full Text	Abstracts, Editorial
Published in English language	Studies defining remission criteria or recovery from any other psychiatric disorders

## Literature Search Strategy

Electronic database searching and manual searching strategies were used to identify relevant studies.

- Electronic database search-'Pubmed'& 'Pro-Quest' Search was done with the help of Boolean operators (AND/OR by using terms identified from the title, abstract or keywords psychosis OR schizophrenia AND recovery OR personal recovery OR subjective recovery AND meaning OR personal meaning OR understanding OR perception\* OR perspective\* OR subjective meaning OR experiences.
- Manual search: The table of contents of few journals and recent literature reviews of related topics were hand-searched to ensure the inclusion of all related articles for reviewing.

## Study Selection

Only studies explaining subjective meaning of recovery was included in this review. Altogether a total of 811 titles were identified and after removing the duplicates there was a total of 758 studies. Based on the exclusion criteria 727 articles were excluded and the remaining 31 articles were screened for eligibility. In the final stage, fourteen (14) studies were excluded based on the content (see Fig. 1) and other seventeen (17) full text articles were included for this systematic literature review.

The details of studies reviewed are listed in the following table, which includes: authors, country and year; aims(s) or objectives of the study and details of the sample



References	Objective	Methodology	Results
Windell et al. [13]	To understand the Subjective experiences of illness recovery in individuals treated for first-episode psychosis (FEP)	Qualitative study 30 participants Interpretive Phenomenological Analysis	Several categories that reflected subjectively important processes of recovery were identified, namely: symptom recovery, reconciling meaning and acceptance, regaining control, and negotiating and accepting treatment
Connell et al. [14]	To explore the subjective factors of recovery associated with the experience of first-episode psychosis (FEP)	IPA was used to explore the experiences of 20 young people who had recently experienced FEP.	Those who reported subjective improvements in recovery were more likely to have developed a meaningful interpretation of their psychosis, strengthened relationships with others, and formed a stronger sense of self
de Wet et al. [15]	To study the experience of recovery from schizophrenia	7 were interviewed	According to the participants, support (Professionals/Families and its natural corollary, having to care for another, are possibly the greatest contributors to the recovery of persons faced with schizophrenia
Connell et al. [16]	Connell et al. To understand the process of change in self and its relationship to recovery in the first 3 months	12 People diagnosed with FEP. IPA	Two superordinate themes were identified: <i>loss of self</i> and <i>strengthening of self</i>
following FEP	Longitudinal Design 3 months follow-up	Themes characteristic of loss of self were revisiting the past, consumed by illness, and feelings of loss. Themes characteristic of strengthening of self were, coping with disturbing thoughts, and finding the positives	
Gopal and Henderson [17]	Trans-Cultural Study of Recovery from Severe Enduring Mental Illness in Chennai, India and Perth, Western Australia	The study reported here involved the comparative analysis of the findings of a study conducted by SCARF in Chennai, with the findings of a study conducted in Perth  The original SCARF study comprised of 100 participants the original Perth study used a grounded theory method with 15 people	The strongest indicators of recovery among the participants of both groups were being symptom free (98%) and regaining social role functioning (82%). There was agreement between the two groups on being symptom free, social role functioning, social inclusion and regaining cognitive process
Jose et al. [12]	A systematic review on Consumer perspectives on the concept of recovery in schizophrenia	25 papers 2000–2013	Recovery was perceived as both process and outcome—A long term process with occasional setbacks and experienced in different phases. By recovering, the individual felt better about self, family and social functioning and was able to live with the disability or overcome the effects of symptoms. Complete recovery only when the symptoms are less and able to live without medicines



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References	Objective	Methodology	Results
Law and Morrison [18]	To establish consensus about the meaning of recovery among individuals with experience of psychosis	10 experts-381 participants Delphi approach	The highest level of consensus was reached for "recovery is the achievement of a personally acceptable quality of life" and "recovery is feeling better about yourself." Personal factors such as having goals and purpose, hope for the future, and motivation to succeed were also felt to be important, in agreement with previous research. Although a high proportion of people felt that not taking medication as prescribed could hinder recovery, the same proportion of people also felt that side effects of medication, such as concentration problems and memory loss, could also hinder recovery
Wood et al. [19]	To explore service users perceptions of recovery from psychosis	Q- methodological approach (N = 40)	The most important statement was 'how much support I get from friends and loved ones' (65%)s. This was followed by, 'how much I have changed as a person since I have had these experiences' (52.5%), 'how my experiences affect my relationships with friends and loved ones' (45%), 'how my experiences affect how positive I am for the future' (42.5%), and 'how depressed my experiences make me feel' (40%)
Beck et al. [20]	To explore subjective judgements of recovery from the perspective of service users	122 participants descriptive	41.8% of participants placed themselves in the "recovered" group, while 58.2% of participants placed themselves in the "not recovered"
			The significant correlations between the measures of recovery and the psychological factors suggest that higher levels of self-esteem and hope, along with lower levels of depression and anxiety, were associated with more positive judgements of recovery
Windell et al. [21]	To examine personal definitions of recovery among individuals treated in a early-intervention service	30-one-time qualitative interview.	Analysis revealed three domains of recovery, namely illness recovery-subjective control over the extent and influence of the symptoms and reduction of distress associated with symptoms. Psychological and personal recovery-regaining a sense of control and a coherent sense of self and social and functional recovery. Two additional distinct recovery themes that emerged were the impossibility of recovery and participation in treatment as a means to recovery



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References	Objective	Methodology	Results
Thara [22]	To study the patients' perspectives On the indicators of recovery	100 Participants Semi Structured interviews	The most common theme was the equation of recovery with the absence of symptoms (88%) and not having any more relapses (73%). Getting back to their regular lives in terms of functioning and being able to handle the associated responsibilities (62%) were also deemed important. To 65%, recovery meant not having to take medicines any more. Patients mentioned internal validation six times more frequently than external validation. Although the group consisted of primarily chronic patients with a mean duration of illness of about 11 years, none thought that recovery was impossible to achieve and all were able to articulate personalized indicators of recovery
Lam et al. [23], Hong Kong	To explore recovery experiences from the subjective perspective of people with FEP	A qualitative methodology was used based on a focus group of 6 members	Recovery meant regaining previous functions, both cognitive and social. Social functions included being engaged with friends and family to maintain a sense of being a normal member of the community, becoming a volunteer, participating in social and recreational activities and being able to hold down a job, following lectures, getting married and having babies. Most did not think that they had fully recovered because they still needed medication and psychiatric support
Roe et al. [24], Israel	To investigate the relation between objective clinical recovery and subjective personal recovery	159 persons Recovery assessment scale, Brief Psychiatric Rating Scale Multidimensional scale of perceived social support (MSPSS) (GAF)	No significant correlation between the total score of symptoms BPRS and the total score of recovery (RAS) and between functioning (GAF) and the total score of recovery. A significant negative correlation was found between symptom severity and recovery for the group with relatively earlier onset but not for the group with relatively later onset. Social support was significantly correlated with self-reported recovery
Henderson [25], Australia	To describe the process of recovery from the effects of a SMI	Grounded theory 15 face-to-face interviews	Recovery from the effects of a severe mental illness involves a process of adjusting to the threefold losses of: (1) mental health; (2) cognition and affect; and (3) social functioning including the loss of a sense of inclusion. Gaining clarity of understanding about one's experiences and achieving peace of mind are important properties of recovery. A person can potentially recover in any one or all of the areas and, therefore, recovery can be complete or partial



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References	Objective	Methodology	Results
Piat et al. [26], Canada	To explore the meaning of recovery from the consumers perspective	60 semi-structured interviews with 54 mental health consumers	Findings revealed two contrasting meanings of recovery. In the first definition, consumers linked recovery to illness, to a cure, to the right medication, or better health. They also saw recovery as a return to their former selves. In the second definition, recovery implied self-determination, becoming actively engaged in a process that would ultimately transform the self
Noiseux and Ricard [27], Canada	Recovery as perceived by people with schizophrenia, family members and health professionals	41 participants (16 people with schizophrenia, 5 family members, 20 professionals) Grounded Theory	Recovery is defined as a 'process involving intrinsic, non-linear progressthat the individual adopts to rebuild his or her sense of self and to manage the imbalance between internal and external forces and regaining a sense of well-being on all bio psychosocial levels.'
Ng et al. [28], China	To investigate the meaning of recovery	8 people with chronic schizophrenia A qualitative methodology based on a 3-h focus group	Recovery implied more than symptomatic remission—they specifically disagreed that a marital or romantic relationship should be included as an important criterion of full recovery. Medication cessation is an important criterion

#### Results

The results of the literature review are presented under two headings: (1) findings on summary of study characteristics (2) findings about subjective meaning of recovery from Schizophrenia.

Of the seventeen (17) papers included in this review, three (3) studies were conducted in Australia [14, 16, 25], four (4) in Canada [13, 21, 26, 27], three (3) in UK [18–20], two (2) studies from India [12, 22], one (1) study each from Israel [24], South Africa [15], Hongkong [23] and China [28] and an India\_Australia Trans-cultural study [17]. Out of the total papers selected for the review, ten (10) studies followed Qualitative methodology—predominantly Interpretative Phenomenological Analysis, and Grounded Theory approach. Four (4) papers used Quantitative methodology for the study. Delphi approach, Q-methodological approach and Systematic Review were the other methodologies adopted by the papers identified in the review.

Of the seventeen (17) studies only five (5) studies have specifically mentioned that the data was collected from patients with Schizophrenia [15, 22, 24, 27, 28].

Three (3) studies were conducted among persons with a diagnosis of Psychosis as mentioned [18–20]. Five (5) studies have mentioned that patients with a diagnosis of First Episode Psychosis (FEP) were recruited for the study [13, 14, 16, 21, 23]. [22] and [24] has included people with a diagnosis of Schizoaffective disorder. [25] and [26] has mentioned people with a diagnosis of Severe Mental Illness were included in the study.

Sample Size varied from 6 to 41 for the qualitative studies and 40–159 for the quantitative studies. The Delphi method recruited 10 experts and 381 patients for the interview. The systematic review, reviewed 25 papers on the concept of recovery. Semi structured interviews, focused group discussions and questionnaire method were mainly used across the studies for data collection.

#### Subjective Meaning of Recovery

The studies mainly explored one of these aspects (a) Meaning/Definitions/Perceptions of recovery and (b) Experiences/Process of recovery. Studies exploring meaning/definition of recovery found that there are



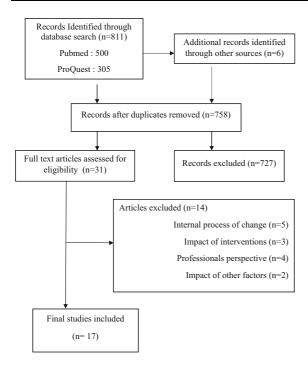


Fig. 1 Study Selection Process

various ways in which people with mental illness see their recovery and attributes meaning to it. The "achievement of a personally acceptable quality of life", "feeling better about yourself", subjective control over the extent and influence of the symptoms and reduction of distress associated with symptoms, regaining a sense of control and a coherent sense of self, a return to their former selves, becoming actively engaged in a process that would ultimately transform the self, regaining a sense of well-being are the various definitions/meanings assigned to recovery subjectively.

Recovery was perceived in different ways by the participants. It was perceived as both process and an outcome. It was perceived based on the support from others, changes in self, absence of symptoms, not having any more relapses, getting back to their regular functioning and being able to handle the associated responsibilities.

The review found that the process of recovery includes factors like developing a meaning for their illness or life, accepting the illness or treatment or a loss, strengthening self or coping and regaining the lost functioning. [12, 18, 22, 28] these studies found

that medication cessation as an important factor to be considered, for a person to recover.

#### Discussion

The review revealed that there are various ways in which a person perceives his/her recovery from mental illness. Since recovery is defined as an individual process, the experiences one goes through influences the meaning one attaches to recovery. Delivering recovery oriented interventions would need a greater consensus on recovery meaning developed from the patient perspective. Studies also found that absence of symptoms as a major factor in the process of recovery, but considering only this would be insufficient.

Clinicians, caregivers, and researchers alike should use both personal recovery and functional recovery indicators [24] as a form of triangulation to improve our understanding of the multifaceted nature of recovery and to demonstrate our commitment to recovery oriented services [29].

Resnick et al. [30] found that, although severity of symptoms was inversely related to a recovery orientation, reduction of symptoms does not automatically lead to psychological recovery. For example, Resnick and colleagues also found that severity of symptoms was not related to hope, the core of the recovery process. It is therefore important to ensure that the achievement of traditional goals is in fact facilitating psychological recovery [31]. To that end, outcome measurement, evaluation studies and research should include assessment of the subjective experience of recovery, as it has been described by the consumers [29].

As everbody's life experiences and circumstances are unique, it may be challenging to apply standard measurement criteria for recovery The literature is also clear that recovery is not a linear process, but a complex, spiral process of small goals and achievable steps, combined with setbacks and periods of growth and insight. For some service users, recovery may mean developing personal resourcefulness to live well in the presence of mental health problems; for others it may be about overcoming 'symptoms' as defined by the traditional model of illness. Consequently, what recovery means for a person is best defined by the individual within the context of their personal wishes, dreams, and capabilities [32].



The findings also highlights the patients need for social functioning as an important element in their recovery process. Community based recovery oriented services can help in attaining this goal. Findings on subjective recovery can also help in development of more measurement tools to assess the same.. More qualitative studies and personal narratives can lead to get an in-depth knowledge about the concept of recovery from schizophrenia.

Orienting mental health service towards recovery will involve system transformation. The research challenge is to develop an evidence base which simultaneously helps mental health professionals to support recovery and respects the understanding that recovery is a unique and individual experience rather than something the mental health system does to a person [33].

#### Conclusion

It can be concluded that recovery is a process that incorporates multidimensional components like, symptoms, functioning, personal adaptation, social support, and development of individualised coping mechanisms. These factors are not mutually exclusive but they all contribute together towards recovery. The importance placed on each factor may vary across individuals, based on their experiences. Many of the studies were cross-sectional and findings were collected mainly at a single time point. It is quite possible that, concept of recovery can change over time, during the person's journey to recovery.

Acknowledgements Funding was provided by University Grants Commission (UGC), New Delhi (Grant No. 1367/NET.DEC.2010).

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