

Recovery in Psychosis: Perspectives of Clients with First Episode Psychosis

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Abstract

Introduction: Recovery from psychosis relates to connectedness, hope for the future, identity, meaning in life and empowerment. The process of recovery is often described as gradual and non-linear, with many stages and turning points, and without a definitive end point. This qualitative study aims to understand what recovery means to clients, to better understand their unique recovery process and what helps in recovery among clients with lived experience of first episode psychosis (FEP) in a developed Asian setting. **Materials and Methods:** The study design and interview guide development included inputs from persons with psychosis, following which 7 focus group discussions were conducted with 40 FEP clients of a tertiary care psychiatric institute. **Results:** Thematic qualitative analysis identified three themes: 1) meaning of recovery (where participants expressed their views on what recovery meant to them); 2) recovery as a journey (due to the constant ups and downs in the long process of recovery, it was often articulated as a “journey”); and 3) facilitators of recovery (related to resources, practices and experiences that supported their recovery). **Conclusion:** The emergent themes provide an understanding of the meaning of recovery to persons with FEP, their experiences as they proceed with their recovery journey and factors they found helpful. The importance of acceptance of the condition and the personal role the individual plays in his or her own recovery was evident in the narratives of the participants. The study suggests a need to incorporate recovery-relevant approaches right from the first episode of psychosis.

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Introduction

The treatment of serious mental illnesses such as schizophrenia and related psychoses has dramatically shifted in the last century. In the early 1900s, asylums were the standard form of care for patients with serious mental illnesses.¹ It was the advent of the first psychotropic drugs such as chlorpromazine in the 1950s that precipitated “deinstitutionalisation” or the shift from large central psychiatric state hospitals to community-based care.² In the last few decades, there has been increasing support to

re-examine our existing model of recovery from mental illnesses from the traditional clinical model of recovery to one that complements it with a more holistic, service user-centred and recovery-oriented approach.^{3–5} The consequent reform to the delivery of mental health care has already emerged in Australia and the United Kingdom.⁶

The traditional clinical definition of recovery from schizophrenia has primarily been focused on symptom remission.⁷ This definition of recovery is predicated on: 1) lessening the severity of psychopathological symptoms,

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2) improvements in psychosocial functioning; and 3) a minimum duration of meeting criteria 1) and 2).⁸ This can be labelled as an outcome-based definition of recovery. Service users, however, have often defined recovery as one that goes beyond an outcome-based definition. In a systematic review by Leamy et al,⁹ the themes of connectedness, hope and optimism for the future, identity, meaning in life and empowerment were found to be associated with personal recovery. This definition of recovery, which can be called the process-based definition of recovery, is well described by Anthony¹⁰ as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness”. There are important clinical implications if service users do not hold onto the same model of recovery as health systems in terms of treatment services to be delivered to service users and their quality of life and user satisfaction.

Service users have defined recovery as recovery from an illness recovery perspective (reduction, elimination or control over their psychotic symptoms), but also from a psychological and personal recovery perspective (understanding the illness, accepting the illness as part of the self and regaining a sense of “self” that existed before illness onset) and social and functional recovery perspective (having a positive social identity through meaningful relationships and also finding meaningful employment).¹¹ Recovery has been often described as a gradual and non-linear process with many stages and turning points¹² without a definitive end point.¹³ Recovery from psychosis has also been described as an ongoing process of dealing with the illness on a day-to-day basis and overcoming challenges as they come without any enduring state of recovery.¹⁴ An investigation of the factors that might contribute to or facilitate recovery from a service user’s perspective provides valuable information to policymakers who are attempting to improve service user’s satisfaction and quality of life. A study by Law et al¹⁵ found that service users had cited social support, knowledge of their illness and self-care and availability of mental healthcare resources as important factors that helped them in their recovery.

Most studies that investigated the concept of recovery from the perspective of service users were in Western populations. There is a lack of studies on Asian populations. In one of the few studies conducted in Asia (to the best of our knowledge) by Lam et al¹⁶ in Hong Kong,

participants’ concept of recovery extended from regaining previous functions (both cognitive and social) to gaining a stronger sense of control over their lives. In Singapore, previous research found that positive re-appraisal, better social support, shorter duration of hospitalisation and higher education are associated with better quality of life and, possibly, recovery in patients with schizophrenia.¹⁷ There is, however, a need for further research in Asian populations with multiethnic groups to investigate whether the findings from Western populations can be replicated in Asia. This, again, will have important implications in the delivery of treatment suited to the idiosyncratic needs of the population.

This study aimed to understand what recovery means to clients with lived experience of psychoses by using a qualitative approach in a tertiary psychiatric hospital in Singapore. Additionally, clients’ perspectives on the process of recovery from psychosis were sought, along with what specifically persons with psychoses found helpful in their recovery.

Materials and Methods

Ethics

Ethical approval for the study was obtained from the Domain Specific Review Board of the National Healthcare Group of Singapore. Written informed consent was obtained from all participants and from a parent, legally accepted representative or next-of-kin for participants who were aged <21 years old (the age of majority in Singapore).

Study Population and Setting

The inclusion criteria for the study participants were clients from outpatient clinics run by the Early Psychosis Intervention Programme (EPIP) in the Institute of Mental Health, Singapore.¹⁸ EPIP clients are provided phase-specific multidisciplinary care that includes appropriate psychopharmacological management, psychotherapy, occupational therapy and group interventions as necessitated. Additionally, every client is assigned a case manager who, via a strengths-based approach, provides supportive counselling, psychoeducation and bridges the various services and maintains contact with them to ensure appropriate care through different phases of their illnesses.¹⁸

The study participants were EPIP clients aged between 18–40 years old who were able to speak and understand English and were deemed clinically stable by their treating team (doctor or case manager) to participate in focus group discussions (FGDs). Potential participants were referred to members of the research team by the treating team. Members of the research team (who were not directly

responsible for providing care for the potential participant) then approached them to participate in FGDs.

A total of 40 participants took part in 7 FGDs that were conducted from May 2017 to January 2018. Each FGD comprised 5–6 participants and lasted between 60–90 minutes. All participants were reimbursed with SGD60 each for their time and travel.

Data Collection

A FGD guide was developed alongside service users with a history of psychosis (Fig. 1). A member of the study team, who was also a service user with psychosis, sought inputs from 2 peers while determining the content and language of the FGD guide. All FGDs were conducted in a community centre outside the hospital by 2 team members, a facilitator and a note-taker, who had experience in qualitative research. Participants who agreed to take part in the study were informed of their rights and responsibilities as a study participant and their consent was obtained for the start of FGDs. The facilitators (MS, JAV, YYL and LC) were researchers who were not involved in the direct care of the participants for the FGDs that they individually facilitated. After discussions among the authors, an interview guide was developed and used to facilitate the FGDs to ensure consistency across different discussions. The FGDs encompassed a set of probes directed to elicit responses from participants on what recovery from psychosis meant to them, how they (would) describe their recovery, what they found helpful in their recovery and how other influences might have impacted both their recovery and their views on recovery.

There seems to be no general rule on the optimum number of focus groups to have in order to generate the maximum number of themes from the FGDs. Guest et al¹⁹ found that 90% of all the themes in their study were discoverable within 3–6 focus groups. However, the generalisability of their findings might still be dependent on factors such as the homogeneity of the sample. In our study, there was relative uniformity, with all the sample experiencing psychosis for <3 years, and with some differences in socioeconomic and educational backgrounds. Study team members met after every FGD to discuss and review data that was generated in an iterative process. After 7 FGDs, it was decided that no new themes were emerging, and that data saturation had been reached. As such, no further FGDs were conducted. All FGDs were audio-recorded and transcribed verbatim. The transcripts were cross-checked with the facilitator for consistency. Participant confidentiality was maintained by excluding all possible identifying information such as names from the transcripts.

Data Analysis

A qualitative thematic analysis methodology was used to elicit meaning from the data collected and to establish themes.²⁰ Using an inductive approach, content of the interviews was coded to allow themes of importance to emerge from the data. The researchers first familiarised themselves with the transcripts by reading through them several times to obtain a broader perspective of what the participants were saying in the FGDs. Subsequently, a code book was developed for data analysis based on the narratives of the transcripts.²¹ A team member with experience of psychosis was involved in the development of the code book and interim coding process and reviews. Coding of all transcripts was performed by 2 researchers (JV and LC) after establishing good inter-rater reliability (0.77 kappa coefficient). Themes were subsequently derived based on the codes from the transcripts. The coding and thematising of data were conducted using NVivo software version 11.

Results

Background of Participants

Participants were aged 18–39 years old with a mean age of 27 years. There were more participants who were women (67.5%), of Chinese ethnicity (65%), never married (95%) and with a polytechnic or other diploma (30%). The sociodemographics of the participants are shown in Tables 1 and 2. All participants were clients of EPIP.

Focus group discussion guide

- What does recovering from a mental condition mean to you?
- When someone says they have recovered from a mental condition, what does it mean to you?
- When does one consider himself/herself in recovery?
- What is your personal goal in terms of recovery?
- When you were first diagnosed with a problem, what were your thoughts/feelings about recovery? Did they change over time? Can you describe your experiences?
- What do you feel/ think about recovery now?
- How can one reach recovery from a mental condition?
- What, according to you, does your recovery mean to your family members/relatives?
- What, according to you, does your recovery mean to the doctors and others treating you?

Fig. 1. Focus group discussion guide.

Most of them self-reported having schizophrenia or other psychoses with a wide variation in their duration of illness which ranged from 5 months to 6 years; 25 (62.5%) of the 40 participants were first diagnosed within <2 years before the FGDs.

Key Themes

From the content of the FGDs, 3 main themes related to recovery from psychosis emerged: 1) meaning of recovery (where participants expressed their views on what recovery meant to them); 2) recovery as a journey (due to the constant ups and downs in the long process of recovery, it was often articulated as a “journey”) and 3) facilitators of recovery (related to resources, practices and experiences participants attributed as being helpful in their recovery). Although there were interrelations and overlaps between themes—which were deliberated upon by the study team—these were eventually deemed to signify different contexts, specifically meaning, process and influences, respectively, and hence retained

Table 1. Sociodemographics of Study Participants

Variable	N	%
Median age in years (range)	27 (18–39)	
Gender		
Men	13	32.5
Women	27	67.5
Ethnicity		
Chinese	26	65.0
Malay	4	10.0
Indian	9	22.5
Others	1	2.5
Marital status		
Never married	38	95.0
Married	2	5.0
Education		
GCE “O”/“N” level/completed secondary education	4	10.0
Vocational institute/NITEC certificate	9	22.5
Polytechnic/other diploma	12	30.0
GCE “A” level/completed pre-university or junior college	6	15.0
University degree	8	20.0
Postgraduate degree (e.g., Masters/PhD)	1	2.5

as separate themes. However, to put the findings in perspective and understand these relations, a broad concept map was developed from the content (Fig. 2).

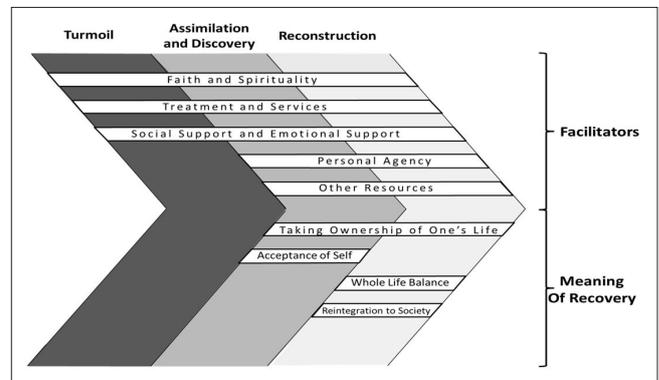


Figure 2: Concept map of recovery-related themes

One: Meaning of Recovery

Four secondary themes on the definition of recovery came up during the FGDs. These were acceptance of self, taking ownership of one’s life, whole-life balance and reintegration into society.

Acceptance of Self

Acceptance came up as a strong theme in FGDs. To the participants, “recovery means also accepting who we are”. Being able to move forward despite their illness was crucial to them. With this acceptance, they are able to start over in life again and “to try again and again”. This involved a change in the outlook on their lives. It may be accepting that they may have to change their initial goals. It also meant that they were able to pursue their interests and hobbies. All in all, it was about being able to accept themselves and “turn to more positives in life” to make the best of the situation that was thrown their way.

From FGD 1: “I think recovery means you find peace in yourself and then you start believing in yourself to get things back in track.”

Taking Ownership of One’s Life

Having control and independence were expressed as key elements in our participants’ recoveries. They voiced the importance of being “back on [their] own feet” and being able to “handle things himself or herself”. The locus of control ranged from not being reliant on external factors to being able to handle challenges at the workplace, and to manage everyday activities such as commuting and going to the movies. A participant noted that “many people live on and live good meaningful lives, even with

Table 2. Background of Participants

Identification Number	Age (Years)	Gender	Ethnicity	Diagnosis*
1	20	Woman	Chinese	Psychosis
2	27	Woman	Chinese	Psychosis
3	24	Woman	Chinese	Bipolar disorder
4	25	Man	Chinese	Schizophrenia
5	25	Woman	Malay	Brief psychotic disorder
6	36	Woman	Chinese	Schizophrenia
7	39	Woman	Chinese	Schizophrenia and anxiety disorder
8	21	Man	Chinese	Schizophrenia
9	20	Woman	Others	Schizophrenia and obsessive compulsive disorder
10	22	Man	Indian	Schizophreniform disorder
11	31	Man	Chinese	Depression with psychotic features
12	21	Woman	Chinese	Schizophrenia and obsessive compulsive disorder
13	25	Woman	Chinese	Bipolar disorder with psychosis
14	27	Man	Malay	Bipolar disorder
15	32	Woman	Chinese	Psychosis
16	29	Woman	Indian	Schizophrenia
17	33	Woman	Chinese	Undisclosed
18	21	Woman	Chinese	Schizophrenia
19	21	Woman	Chinese	Psychosis
20	36	Woman	Indian	Bipolar disorder with psychosis
21	24	Woman	Chinese	Bipolar disorder
22	27	Man	Chinese	Undisclosed
23	25	Man	Chinese	Schizophrenia
24	29	Woman	Chinese	Schizoaffective disorder
25	27	Man	Malay	Brief psychosis with affective symptoms
26	35	Woman	Indian	Psychosis
27	18	Man	Chinese	Undisclosed
28	20	Woman	Indian	Attenuated psychotic disorder
29	24	Man	Chinese	Undisclosed
30	26	Woman	Chinese	Depression
31	26	Man	Chinese	Schizophrenia
32	28	Woman	Malay	Schizoaffective disorder
33	24	Man	Malay	Schizophreniform disorder
34	34	Woman	Chinese	Psychosis
35	39	Woman	Malay	Schizophrenia
36	24	Woman	Chinese	Mild delusional disorder
37	23	Woman	Other	Psychosis with anxiety depression
38	25	Woman	Chinese	Bipolar disorder
39	23	Man	Malay	Psychosis
40	37	Woman	Chinese	Bipolar disorder

*Self-reported by participants

symptoms”. To them, it was about having the freedom to make decisions that were not based on their fears and disabilities, but to pursue their hopes and dreams.

From FGD 7: “[Recovery] starts when a person starts taking ownership of their health ... I would define a person [who] will start having recovery when they begin to take charge of their own life, their own health, taking deliberate steps towards moving towards recovery, and not depending just on people around them.”

Whole-Life Balance

Most participants also highlighted the importance of symptom remission and regaining function as a definition of recovery. They cited the ability to function in regular daily life as recovery. Focusing on whole-life balance, participants mentioned simple things such as eating normally, socialising normally and managing emotional well-being as part of symptom remission. Besides symptom remission, being able to “control mood and temper” also came up as an important aspect of recovery.

From FGD 6: “A recovered person should be physically well, mentally stable, emotionally stable.”

Reintegration into Society

For most participants, recovery was about reintegrating back into the society in their age-appropriate roles (school, family or work). For instance, a participant shared that she fell ill halfway through her internship. Now that she’s back in school, “completing [her] internship is very important”. Going back to their previous roles at home, in school or at work was crucial to their recovery. Some of the participants also perceived being able to reduce and eventually stop their medication as relevant to their reintegration.

From FGD 2: “To me [recovery] will look like they have stopped medication and they resume to their previous roles in society like they have gone back to work, gone back to school, whatever they have been doing previously.”

Two: Recovery as a Journey

Recovery was perceived to be a “journey” by a number of participants who felt there was no specific end goal or a fixed final destination for them. Each journey was believed to be a very personal experience with a unique trajectory for each individual. A few participants mentioned that it was a journey they took more than once.

As narrated by 1 participant from FGD 4: “So after my second recovery, I realised that recovery is not final and that like what you said about the journey, to extend the metaphor, like the paths are very meandering, sometimes there are many fault paths and sometimes we even meet

cliffs and all that. So there’s a lot of internal and external so-called traps and obstacles to your own recovery, and sometimes you just have to find another way around it. There is no one fixed-route.”

Three distinct phases in their recovery journey were described by participants during FGDs. First, the phase of “turmoil” which the participants went through when they had their first episode of psychosis and recovery seemed a very distant destination. Second, the phase of “assimilation and discovery” which started as participants described coming to terms with their condition, slowly accepting it, understanding it and started working on it. Third, the phase of “reconstruction” when participants began building and utilising their personal, social and external resources towards their recovery.

Turmoil

Participants shared experiences of the time when they had their first episode of psychosis. A number of them shared being “hit out of the blue” with minimal prior signs and insight into the condition. They described being very scared, confused, in chaos and denial and feeling hopeless about the possibility of recovery at this stage. Expressions of anxiety, disbelief, anger, guilt and withdrawal were common across the participants and FGDs. Many found themselves in conflict with themselves, their families and at times with the treating clinical teams.

From FGD 1: “When I first heard voices and all that, I felt very fearful. I felt like somehow or rather it’s as bad as though the world is going to end. That kind of fear I felt. Very fearful, even to my case manager or my own mom. I was very afraid of like what’s going to happen.”

From FGD 4, “When you are first hospitalised and you are so isolated in your own ward or you don’t even know what the heck is happening to you, it’s very hard to even conceive for recovery or to conceive that you are ... you are just totally in denial, or like it’s just very hard press ... everything is like a confused jumble around you, so you just cannot conceive anything more than whatever is in front of you, whatever you are facing right now.”

Some of them expressed having very low self-esteem during this period and feeling desperate to get better soon and recover as fast as they could without specifically knowing what this entailed.

From FGD 4: “We think no hope. No hope, really no hope. How can we recover, we are so desperate to get well, but it’s very difficult to get well.”

However, a small number of participants also described being relieved when they knew exactly what was happening to them and felt that was a turning point in their journey even while they were still quite unwell.

From FGD 5: “I think I was aware for a while that there’s something going on. At first I thought it was like a stress disorder or something. For the longest time I thought I was depressed. So I saw a counsellor for that. A lot of the symptoms you realise that it’s similar, you know? Low energy, lack of happiness, distrustful. It really didn’t occur to me that it could be something psychiatric in nature. So when this thing came, like he said I was quite relieved. Cos only through diagnosis can we treat it.”

Assimilation and Discovery

This phase in the journey was described by participants as the time when they started accepting their condition. Many of them mentioned that since their first experience with psychosis, they had accepted that they were a different person “than their past self”, the change in their circumstances as they now “had this illness” and that the illness was a part of them.

From FGD 1: “It’s like a journey because we are no longer the same people as how we are used to be. So it’s about adapting to changes. And trying to like adjust our needs more.”

From FGD 6: “It’s more about coming to terms with the experience itself and I think taking ownership over the experience. I think for me I would have actually recovery ... the term recovery if let’s say I would say ‘yeah it happened to me but I’m fine with it.’ You know, this is part of who I am and I am also able to then move past it.”

With this acceptance came the need to develop insight into their diagnosis. Many read about mental disorders and available treatments on their own, discussed with peers and clinicians, or attended talks and/or therapy to find out more about what to expect and how to deal with such situations.

From FGD 1: “It’s also being aware of like your diagnosis, like what is the illness, what does it actually mean. So I tried to like find out more about like this illness and see how it relates to me.”

This period was also perceived as period of “discovery” and “self-reflection” where participants started discovering more about their illness, themselves, their “limits” and what triggers maladaptive behaviours in them and about life in general.

From FGD 1: “It’s about being authentic. Because I think that when you are being true to yourself, you are able to see where are your limits and from there you can know what are the more proper treatments for you.”

From FGD 3: “I started to have, for some people it may seem delusional, but for me there are some things that I discovered or been through things like that like, to me

recovery was that being able to make sense of everything that was what I thought of recovery” and “I just feel like going through this whole experience has made me discover the much more human side, aspect of life la. That’s what I feel la, life is fragile, it’s very delicate. That’s what I discovered.”

Reconstruction

As the participants transitioned from acceptance of their illness and discovering themselves, they described their onward “bumpy” journey towards rebuilding their lives. A “loop” of dealing with ups and downs was expressed. This included their experiences of slowly going back to the society they belonged to and re-forming their identity and place. Participants mentioned that dealing appropriately with day-to-day issues they face such as personal challenges, stigma and medication side effects formed a considerable part of their recovery journey.

From FGD 1: “I slowly found the motivation to slowly go back to society.”

From FGD 6: “Family, friends, sometimes your employers also, your colleagues. They tell you to get off medication, to them it’s an expectation of recovery but it’s not realistic. And it affects you because it affects your sense of self and what you are able to do.”

From FGD 3: “I gained like 13 kg ever since I was being placed on (name of medication). Yeah, so now I’m trying to lose all the weight I gained. And then it also caused me to have insomnia and no appetite.”

Reconstructing their life included a number of players and factors, and the different roles and contribution each had in the participants’ journey. These included taking medications, seeking advice and support from professionals and drawing strength from close relationships.

From FGD 3: “Take your medication, that would be number one. Make sure you have a very supportive circle of people that are around you so that you’ll be able to recover faster, and being very honest with the doctors about how you are feeling and how your medication is working on you.”

From FGD 1: “Things like, you didn’t take medicine, or things like you know you still struggle with delusion or hearing voice. But you know that there are people there to help. And that is when you know that you are able to face recovery, with a bolder heart. It gives you that courage to be able to help you face the challenges in life.”

Continuing to take medications was, however, perceived by a small number of participants as a constant reminder that they were “not normal” and that they could never fully

recover. Not being on medications was mentioned during the FGDs and perceived as a benchmark for recovery by some participants. To them, taking “no medication” and having “no relapse” were key factors in recovery.

From FGD 6: “I have a problem with medication to be honest. Because I think when you are made to take medication like, there’s this constant reminder like for me I’m still on medication and I’m technically supposed to be taking it every night but I kind of do it alternate night because I don’t feel like I actually need it.”

However, a participant proposed there was need to look beyond medication and focus on their personal meaning of recovery.

From FGD 1: “You can continue [to] go for treatment but you might not end up on the recovery journey. So it’s very important to really make and create your own meaning of recovery, what is recovery to you and see how much and where are the treatment that really helps in your recovery journey because [for] some people [it] could be medicine but some people could be both medicine and probably psychotherapy and probably seeking other professional help. So I think that’s when learning about yourself is also very important.”

In this vein, almost all the participants shared how they took control of their own situations while encountering ups and downs, including behaviour modifications and self-appraisal. Many reported adapting their approach and expectations by setting goals for themselves yet at the same time going slow, pacing their studies and work, being open to whatever comes their way, choosing how to react and being strong, patient and positive. In terms of sustaining a healthy outlook while recovering, participants reported keeping themselves active, positive and calm, expressing themselves, confiding in others, doing new things and “going outside”.

From FGD 3: “I’m doing things one step at a time, that means to monitor the secondary anxiety and to go through the resilience model. And if I get to go for the cert[ificate] in peer support right, I will enter it. Then after that, if not, then I will apply to be a social worker, one step at a time” and “I also learn that you cannot really change other people, or maybe what they say or what they think. But you can like try to change yourself, like you cannot find this sympathy or acceptance from someone else, or may be this is something you can give yourself.”

From FGD 1: “It’s like what you all say, like exercise, positivity. But I feel that it is not something that we can do every day. Like you can’t just be happy and positive. There are times that you will feel vulnerable and we will cry. And there are times that we will face things like,

we might have another episode of relapse. But the most important thing is to know that there are people there for you. And it is okay and it’s alright to be vulnerable and honest and be open to them.”

Despite these positive developments, some expressed residual reservations about being able to fully accept their illness and being symptom-free. The possibility of a relapse was also something that weighed on most of the participants’ minds, and they expressed that it was something they were always mindful of and felt vulnerable about.

From FGD 6: “But now also like what [FGD participant] says, that yeah, it’s about careful of not being in the relapse again. Must gauge your emotional stability, is it stable, if not stable, must see doctor yeah.”

From FGD 1: “It’s like a process. So it’s a continual process. Because sometimes when life shows you a difficulty, then you might go down. But you just need to learn to bounce back. So to say completely recovered; because anything can happen, you don’t know relapse in the future might happen. Especially when you are going through a hard time.”

Three: Facilitators of Recovery

Participants expressed several facilitators to their recovery that acted and overlapped at various stages in their recovery process or journey. The secondary themes that emerged were: personal agency, social and emotional support, treatments and services, faith and spirituality and other resources.

Personal Agency

Personal agency referred to the role the individual played in their own recovery, in terms of both the active steps participants might take or the characteristics participants might adopt that facilitate recovery. This included taking active ownership over one’s physical and psychological health by taking up activities like sport and exercise and any recreational activities that one might enjoy and find relaxation in, as well as eating healthy and getting sufficient sleep. Additionally, being disciplined in taking one’s medications on time and having awareness of the effects of medications on the self were also highlighted. Participants also strongly advocated the need to have a positive and optimistic perspective on life and its challenges, as well as being resilient and independent. Additionally, the social aspect of going out and engaging with others (even if initially distressing) and communicating personal problems with people that they trusted were also deemed as taking personal agency over their recovery.

Lastly, taking steps to gain knowledge and awareness over one's condition, experiences and emotions were raised as important in enabling participants to make important decisions over their well-being and their illness management. This might be through researching on one's condition or journalling one's thoughts and emotions.

From FGD 3: "I think it's also need to like, try to gauge my own like, my emotions la. Maybe if like, if you are unhappy, some people will be like, it's normal la life you cannot always be happy but then I like learn how to gauge if I'm really under a lot of stress and maybe if I'm very unhappy. I try to regulate it la, I won't treat it as nothing. I'll be like oh, I'll be more conscious about it."

From FGD 6: "So it's so important for everyone I think to be empowered with the ability to research and to find out and to be equipped with knowledge so that you know you can make better decisions with regards to how you want to further your recovery process, so I think that's one."

Social and Emotional Support

Social and emotional support came up strongly in its role in facilitating recovery among the participants. The physical support of loved ones such as family and friends being there during times when the participants were feeling down or admitted to the hospital was raised as being helpful in providing hope and courage to the participants in their recovery. Additionally, having an understanding of the illness from family and friends was also deemed important so that it allows them to be alert to any signs of impending relapses and thus getting the appropriate help.

Alternatively, this understanding might just allow them to empathise with the participants. These loved ones might then be inclined to help in regulating any distressing emotions of the participants that are associated with the challenges of daily life through simple advice and encouragement.

From FGD 2: "After [hospital admission] erm, I think it is a, it's a good thing that they (parents) were very patient with me, and they really listen to the doctor and like erm I mean like they, they know that it's part of my condition and they know how to handle it because like I will get very moody and then I get very emotionally then erm, then I was very irritable also and then erm ... yeah they were be basically very patient with me la then they just erm reassure me that there will be a better every day."

From FGD 6: "When I'm working, when I'm stressed or whatever, when my boss see me as stressed, they will tell me to rest. That helps a lot. That's why it doesn't affect me but it helps me a lot because when they have learnt and accept, it become a helpful term for you instead of an affecting point."

Treatments and Services

This theme encompassed medical and psychosocial management by healthcare providers that facilitated their recovery. Participants acknowledged the role played by their psychiatrists and case managers in their recovery where they talked about the trust they had in their psychiatrists as an expert who knew best about the efficacy of medications while the case manager was described as someone who helped them navigate the health system as well as supported their education and workplace needs.

From FGD 3: "And my psychiatrist actually told me it's perfectly okay to live your life as normal and when I was making decision on whether I should choose like the more competitive schools or I should downgrade and choose the less competitive schools because of my current situation, he encouraged me to just go for whatever choice that I would think I am fit for without thinking I have this diagnosis."

Participants also talked about the role of medications, therapy and counselling in their recovery. While medications provided control over their symptoms, therapy was seen as helping them understand themselves better, cope with emotions and problems in a positive manner and counselling gave them an opportunity to express themselves without being judged. Meditation, relaxation techniques and mindfulness were also stated to contribute to recovery. Psychosocial interventions comprising structured and unstructured activities played a significant role in participants' recovery.

From FGD 1: "I think psychotherapy helped me in learning how to embrace and accept myself, not just in my symptoms but with regards to other issues also."

Carrying out these activities successfully instilled a sense of confidence in the patients and gave them a space where they could meet people from their own age groups and with similar interests who became part of their social circle and support. The activities indirectly helped them understand that they were not alone in the journey and there was a community they could tap on to learn from as well as contribute to. This created a recovery culture and instilled a sense of hope through the success of their peers as well as understanding that even renowned people suffer from schizophrenia.

From FGD 4: "But it helps what because it create[s] an ecosystem, a recovery culture whereby people with same similar experience can come together and support each other" and "To see the art work, showcase, exhibition by someone who has ... the artist actually has schizophrenia herself, a Japanese artist XYZ."

Faith and Spirituality

While not brought up by a significant majority, faith in God and spirituality were raised as important contributors to recovery of the participants. Some participants felt that a belief in a God assured them that they were not alone when battling their mental condition, while also allowing them to be more accepting to things that have happened and inspiring hope for the future. Additionally, praying or meditating and seeking help from religious leaders were mentioned to help in alleviating personal anxieties and gaining clarity over their experiences.

From FGD 7: “Religious spiritual component is helpful la. I believe it’s ... it’s what is it ... it’s making you be more calmer, and err be more err receptive or accepting of things that happened. Because some people believe that ... believe in God, so they believe that it’s a course, it’s a life process, so they have to be accepting of the process that control them, that control in life la.”

Other Resources

This theme included references, support received from peers, as well as open communication with them about their struggles and strengths. Participants mainly talked about how sharing their own story, owning their story and hearing about other people’s stories of survival enabled their recovery. This theme emphasised the importance of both support groups and peer support groups in recovery. Participants felt that hearing about the experiences of others helped them feel that they were not alone in their journey. Sharing their stories reaffirmed their recovery and reminded them of their strengths.

From FGD 3: “To know, to hear about other persons who are in the recovery stage also, to know about that has helped me. Because I can see that I’m in some sense not alone, that there are other people going through the same thing, so it has helped me.”

From FGD 7: “Sometimes when you share your story, it’s like owning your story. And when you say that I’ve been through this, and I’ve overcome that, and being able to say them out, is like living it all over again. Yah. Like reinforcing the positive attributes of yourself, when you are sharing la.”

Four: Concept Map

Based on the content of the FGDs, a broad concept map was developed to visualise the perspectives on recovery and understand how the various factors and components related to the secondary themes in the 3 main themes. Figure 2 illustrates the key observations. Based on the narratives of the participants, various facilitators

belonging to 5 broad themes were interspersed with layers of their recovery journey while only 3 were mentioned in conjunction with the trauma layer; all 5 themes came up during the next 2 layers.

In summary, individuals reported deriving the meaning(s) of recovery only after they had accepted their condition. At the beginning of their journey when they were in turmoil, they had not even thought about, let alone defined, what recovery meant to them. The only facilitators reported to have helped advance their journey were faith, treatment(s) and emotional and social support. As they progressed through the ups and downs in their journey, the other enablers and personal agency were mentioned. Upon experiencing the various layers of their personal journey, participants reported emerging with 4 broad meanings on recovery from psychosis (Fig. 2).

Discussion

Schizophrenia and related psychoses are considered chronic mental conditions with fewer instances of complete remission. The diversity of psychiatric symptoms experienced during an episode such as hallucinations, delusions, paranoia and/or withdrawal are often accompanied with fluctuations in mood and anxiety which pose several challenges to the individuals’ functioning and recovery. To further compound the impact, these illnesses often affect individuals at their most productive and formative years by disrupting educational, occupational and social progression.²² Lately, research in the field of psychosis has delved beyond treatment effectiveness and clinical outcomes to identify facets of mental health-related stigma^{23,24} and personal recovery perceived by individuals with psychoses.^{9,25-8} Seeking understanding into recovery as defined by the individuals and exploring ways to foster it can enhance client-centeredness, improve outcomes and provide a structure to plan new and appropriate clinical approaches.⁹ However, this is an emerging area of research. Much of the available information has been derived from Western populations where there is a more open dialogue on mental health. This study obtained insights into the concept of recovery as perceived in a non-Western society and in individuals who are in the early years from their diagnosis and who are still recovering. To the best of our knowledge, this is the first study to explore perceptions on recovery in multiethnic Asians who have experienced their initial episode(s) of psychosis.

The study identified 3 main themes related to perceptions around recovery in psychosis. For each theme, secondary themes were synthesised which were of relevance from the perspectives of individuals with psychosis. The themes identified in this study showed a number of similarities

with literature from qualitative investigations carried out elsewhere. A review conducted on qualitative studies in service users with psychosis identified 3 themes—recovery journey, facilitators and barriers to recovery.²⁷ The recovery journey as identified from the review started at a point preceding the episode of psychosis where users described their prior self. The rest of the journey was almost identical, albeit with some variations. The phase of turmoil reported by our study participants centred around expressions of a time they felt severe emotional chaos. However, the review also found that participants often expressed how they were trying to make sense of their experience which was not described by our participants. Likewise, the emphasis on “learning from the episode of psychosis” identified in the review in relation to our second theme on integration was not expressed by our participants. The experiences in the last phase of the journey—rebuilding—were, however, replicated in our study. Another conceptual framework of personal recovery from mental illness derived from a systematic review and expert consensus⁹ identified 3 components that comprised 13 characteristics of the recovery journey, 5 processes of recovery and descriptions of recovery stages where the authors delinked journey from stages of recovery. While they listed the attributes of the journey such as being a process that is also a struggle and multidimensional in its nature, the chronological steps of recovery were mapped into a theoretical model of change starting with “pre-contemplation” and ending with “maintenance and growth”.⁹ There were, however, several common themes between this review and our study. Regardless of the differences in classifications and nomenclature, the take-home is that the recovery journey is often long, variable and complex. Hence, it is crucial that clinicians assess the phase individuals with psychosis are at and the unique challenges and situations that surround them to plan appropriate support and treatment for their clients’ personal recovery.

Another important perspective is the emphasis on taking ownership of one’s life, personal agency, self-acceptance and self-appraisal that was strongly expressed by our study participants. Personal agency was also identified as a recovery facilitator by Wood and Alsayw.²⁷ In their phenomenological investigation of young people with FEP to explore how subjective factors in the first stage of recovery impacted treatment outcomes, Connell et al²⁶ reported 2 superordinate themes that related to “self-estrangement and self-consolidation” and “making sense after traumatic events”. Their findings were also based on the dialogical approach of Lysaker and Lysaker’s²⁹ which proposed that an enriched sense of self can improve personal recovery from psychosis. Strauss³⁰

highlights that “how a person thinks, talks and reflects” can determine “their capacity to adjust and resume a normal developmental pathway”. Hence, it is necessary to develop and equip individuals with the tools to manage their conditions.

It should be noted that the process of eliciting experiences from participants’ narratives in FGDs resulted in several themes that overlapped with each other. Similar results were found in other qualitative studies where the themes intertwined “on a continuum” and were repeated multiple times in participants’ narratives. However, the context of the content determined their position in the coding framework. In this study, the concepts of “acceptance” and “personal agency” were repeated across the 3 main themes. While recovery meant being able to accept themselves and their condition as reported by the participants, it also emerged as a key turning point in the journey towards recovery as well as a facilitator of “personal agency”. Likewise, “personal agency” was repeated under meaning of recovery in the form of “Taking ownership of one’s life” and served as a major facilitator in the reconstruction phase of the journey. Repetition of secondary themes in >1 superordinate or main theme is accepted in qualitative research. In instances of “concordant themes” that are closely inter-related, a concept map is often derived to understand the intricacies of these linkages.^{21,31} We developed a simple concept map based on the secondary themes following content analysis (Fig. 2). This exercise helped in an understanding of how efforts can be focused in view of the personal recovery of individuals with psychosis.

It is evident from our schematic map and available literature that participants report having very little understanding or resources on recovery during the early episodes of psychosis.⁹ This is a critical time in the period of individuals, particularly those who are experiencing psychosis for the first time. Appropriate support from professionals, treatment and, more importantly, family were described as being helpful during this period when participants were struggling with the trauma and had low personal capacity. It is therefore worthwhile to develop and empower external resources including the family of individuals with FEP. This inference resonates in research conducted elsewhere among caregivers of service users that highlights the collective responsibility of all stakeholders to address the unmet mental health needs of individuals.^{33,34} A study from Australia had identified the needs of carers of people with psychosis as those that related to greater involvement of family in treatment

plans, information sharing and transparency, support for the carers and choice of care.³⁵ Likewise, a study of professional carers highlighted several challenges faced by them in adopting recovery-oriented approaches in mental health that were related to training, ownership and shared responsibility.³⁶ This study highlights the significance of understanding and enhancing external support for individuals with psychoses when they are unable to assist themselves, and this could serve as an important area for future research.

This study also indicates possible cultural influence on recovery perceptions in Asian populations. Drawing upon strengths from faith and social and emotional support from family were regarded as important to the recovery process by our study participants. Minority ethnic populations in Western societies were previously found to emphasise stigma and spirituality and were identified as culture-specific notions in recovery.⁹ Our study supplements this literature. Additionally, our study highlighted the relevance of family and social support that is a hallmark of collectivist societies. Our results are in line with a recent article that explored cultural diversity in mental health.³⁷ Gopalkrishnan³⁷ emphasises the impact of social norms on mental health policy and practice and reports 5 key components that vary in Asian cultures—emotional expression of symptoms, shame, power distance between health professionals and users, collectivism and social support and influence of spirituality and religion. Our findings reflect some of these factors and help in understanding the notion of recovery in Asian settings.

The study provides understanding on some key aspects of recovery in psychosis; however, it has some limitations. Individuals included in this study were receiving treatment with an early psychosis intervention that used a structured approach to case management and treatment. There was also an emphasis on client empowerment whereby case managers introduced ways and opportunities to regain functioning and productivity. A number of secondary themes identified individual capacity and drive to achieve recovery targets. It is possible that some of the content may be a result of the training imparted during psychosocial activities conducted by EPIP which uses a risk reduction approach for its clients.³⁸ Most of the participants had a history of psychoses of <2 years and were under more intensive case management interventions. Moreover, given that this study included current clients of EPIP who were well enough to provide consent and were comfortable with describing their personal experiences in a group, the perspectives obtained in this study may relate more to stable clients

than individuals with a longer duration of illness and treatment defaulters who are no longer under the purview of EPIP. The study also did not explore, in detail, how the personal goals of individuals had changed since their illness and how that might have affected what they perceived as their recovery. Additionally, the scope of the study was restricted to clients' perspectives; consequently, the experiences of those who were engaged in their care and treatment, such as informal and formal caregivers, were not included in the analysis.

Conclusion

This study presents clients' perspectives on recovery in psychosis. The emergent themes provide understanding into what recovery means to them, their experiences as they proceed with their recovery journey and factors they find helpful in this journey. The significance of acceptance and personal role in the recovery process is highlighted in the narratives of clients with psychoses. The study also indicates a need to incorporate recovery-relevant approaches as early as during the first episode of psychosis by engaging carers. Given that this study obtained perspectives of only 1 key stakeholder group—the clients—it would be useful to explore perceptions of recovery by family and professionals for comparison and to develop a comprehensive map of the recovery trajectory.

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