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ORIGINAL ARTICLE

Service users' perceptions of recovery from recent-onset psychosis and their long journey to and through psychiatric treatment

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Abstract

A growing body of evidence highlights that individuals' understanding of mental illness and recovery influences their mental health care preferences. Journeys to psychiatric care settings vary across regions with different socio-economic and developmental characteristics. However, these journeys in low-income African countries have not been well explored. This descriptive qualitative study aimed to describe service users' journeys to and through psychiatric treatment and explore their conceptualizations of recovery from recent-onset psychosis. Nineteen adults with recent-onset psychosis were recruited from three hospitals in Ethiopia for an individual semi-structured interview. Data from in-depth face-to-face interviews were transcribed and thematically analysed. Participants' conceptualizations of recovery are summarized into four themes; "domination over the disturbance of psychosis", "complete medical treatment course and stay normal", "stay active in life with optimal functioning", and "reconcile with the new reality and rebuild hope and life". These perceptions of recovery were reflected in their accounts of the long and hurdled journey to and through conventional psychiatric care settings. Participants' perceptions of psychotic illness, treatment, and recovery seemed to result in delayed or limited care in conventional treatment settings. Misunderstandings about only requiring a limited period/course of treatment for a full and permanent recovery should be addressed. Clinicians should work alongside traditional beliefs about psychosis to maximize engagement and promote recovery. Integrating conventional psychiatric treatment with spiritual/traditional healing services may make an important contribution to early treatment initiation and improving engagement.

KEYWORDS
journey to treatment, mental illness, recovery conceptualization

INTRODUCTION

Psychiatric care service users with recent-onset psychosis often come into contact with psychiatric care settings after significant delays and this can affect their recovery (Veling et al., 2019). Individuals with mental illness in low-income countries have been reported to disengage from psychiatric care and seek spiritual or traditional treatment (Burns & Tomita, 2015; Nicholas et al., 2022). This is mostly due to their own, their families' and their community's attitudes and understanding of mental illnesses and recovery (Lilford et al., 2020; Nicholas et al., 2022).

Recovery from mental illness has been defined from two perspectives, i.e., clinical recovery and personal/subjective recovery. Clinical recovery from mental illnesses is commonly defined as improvement in signs and symptoms (Davidson et al., 2008) and a return to some level of functioning (Jaaskelainen et al., 2013).

Subjective recovery is a journey of modifications in one's attitudes and goals (Anthony, 2000) and living a purposeful life as defined by the persons themselves (Slade, 2009). Subjective recovery from mental illness is an area of interest for research and those diagnosed with such illness (Temesgen et al., 2019). However, there seems to be no clear consensus on the definition/concept of personal recovery and thus there are varied views about the process and mechanism of enhancing or achieving recovery from mental illnesses such as psychosis (Jose et al., 2015). Therefore, it is important to understand the conceptualization of recovery from the perspectives of service users with recent-onset psychosis. Several studies and reviews have been conducted on recovery from psychotic illnesses; however, the majority are focused on schizophrenia and understanding clinical recovery from symptomatic and functional perspectives (Jaaskelainen et al., 2013; Jose et al., 2015; Temesgen et al., 2019).

The extant evidence highlights that subjective recovery is often conceptualized as an outcome that individuals with recent-onset psychosis should achieve or fulfil (Hassan & Taha, 2011; Menezes et al., 2006; Temesgen et al., 2019). Bouncing back to a premorbid state of health has also been considered as an important indicator of recovery (Bourdeau et al., 2015; Connell et al., 2015; Eisenstadt et al., 2012). Self-control, gaining hope, living a meaningful life and having a vision/goal to live for are among the identified defining indicators of recovery (Connell et al., 2015; Slade et al., 2012).

Recovery is not merely an outcome, and it is rather a process of achieving several desirable outcomes such as regaining autonomy, self-reliance and symptom control (Connell et al., 2015; Lam et al., 2011; Romano, 2009). In accordance with the potentially enduring nature of psychosis with highly possible symptomatic relapses, subjective recovery is characterized as a multidirectional, individualistic and nonlinear process (Bourdeau et al., 2015; Connell et al., 2015). In summary, individuals with psychotic disorders perceive subjective recovery in quite diverse ways among societies with different cultures and socioeconomic development levels. Research on subjective recovery from recent-onset psychosis is in its early and exploratory stage, and almost all published studies originated from Western countries with a lack of evidence from the Sub Sahara African region.

In low-income, particularly African, countries very low proportions of individuals with psychotic illness seek psychiatric care from conventional psychiatric services, and the majority often disengage from treatment (Nicholas et al., 2022). The problem of mental health service access in Africa is illustrated by the World Health Organization (WHO) estimates that in low-income countries only 20 per 100 000 population are treated for psychotic illnesses at specialist services, while it was 324 per 100 000 in high-income countries (World Health Organization, 2015). In Ethiopia, like many other low-income countries, a small proportion of people with mental illness (5%–10%) receive psychiatric care from conventional institutions (Fekadu & Thornicroft, 2014). There is a significant delay in the treatment initiation (Bekele et al., 2009; Teshager et al., 2020) and high levels of disengagement (Hanlon et al., 2019; Tesfay et al., 2013). With only one specialized psychiatric hospital for over 120 million population, the mental health care service in Ethiopia is integrated with the general health services (Hanlon et al., 2019). However, while this does not meet local needs, most people prefer traditional/religious healing services for their accessibility, affordability, and holistic and contextual acceptance (Hailemariam, 2015; Nicholas et al., 2022). Preference for these services, as opposed to specific psychiatric services, needs careful consideration within the given context of understanding the specific needs of service users' conceptualization of recovery and what interventions would better enable them to achieve personal recovery. Therefore, understanding the specific needs of service users' conceptualization of recovery and treatment is vital (Munson et al., 2022).

The journey to psychiatric care settings and the concept, process, and outcome of recovery from psychosis could be very different between developed and developing countries/societies, due to unique cultural and contextual factors (Iyer et al., 2010). Therefore, research on the journey to conventional psychiatric care services, engagement with care and conceptualization of recovery from psychosis in a low-income country is crucial to understand and hence to promote recovery. There are social and clinical demands for a better and clearer understanding of these concepts/constructs, which can be the prerequisite for designing and implementing evidence-based mental healthcare for service users concerned in African settings.

Objective

To describe service users' journey to and through psychiatric treatment and explore their conceptualizations of recovery from recent-onset psychosis.

METHODS

Study design and samples

An exploratory descriptive qualitative research approach was employed as it gives participants a voice and ensures the presentation of their perspectives in detail. This approach is suitable to describe the nature of phenomena or experiences (Sandelowski, 2000, 2010; Seale, 2011). A descriptive qualitative study "recognises the subjective nature of the problem … patients' experiences of illness and associated healthcare interventions" (Doyle et al., 2020, p. 444) making it fit for the objectives of the current study. This design was also selected for the

current study as it was not conducted with a predetermined structured conceptual framework, and an inductive approach was applied (Sandelowski, 2010).

The required number of participants was determined at the point of data saturation by doing concurrent data analysis (Polit & Beck, 2010). In this study, data saturation was considered achieved when no new relevant data was emerging, all codes, categories and themes were developed and relationships among the themes were well established (Saunders et al., 2018).

In this study, data saturation was achieved at 15 participants and four more participants were interviewed for member checking, cross-validation and testing the data iteration. Hence, 19 individuals with recent-onset psychosis who were engaged in follow-up psychiatric treatment at three referral hospitals in Ethiopia were involved. To achieve maximum variation (Sandelowski, 2010), participants were purposively selected for being diagnosed with recent-onset-psychosis per the DSM-5 criteria (American Psychiatric Association, 2013) and having different levels of subjective recovery scores as assessed by a questionnaire about the process of recovery (QPR) (Law et al., 2014) which was administered in a 9 months longitudinal study conducted before these interviews (Temesgen et al., 2020). Participants also needed to be mentally competent to comprehend and answer questions.

This research was conducted as part of the first author's PhD study. This manuscript is generated from the data collected for the PhD fulfilments (Temesgen, 2020).

Data collection

Ethical approval to conduct the study was obtained in Hong Kong and Ethiopia. Written informed consent to take part in the study was also obtained from each participant prior to commencement.

The interview questions were mainly open-ended with probes to follow-up and ask for more information by focusing on specific aspects of the topic. A semi-structured interview guide was developed based on relevant literature on the topic (Bourdeau et al., 2015; Connell et al., 2015) and the clinical experiences of the research team in the care for people with psychosis. Questions inquired about service users' experiences through their recovery journey, for example: "Please tell me about what has been happening with your mental health since you started treatment?". In this question, participants were encouraged to chronologically describe their journey until the day of contact. "What does "recovery" mean for you?" also with follow-up questions such as, "What indicators could you mention to say you are recovered/recovering/?" was also asked. The interview guide questions were translated into Amharic and validated before use by relevant stakeholders including mental health professionals and service users with recent-onset psychosis. This group of stakeholders was asked to comment on interview guide questions in terms of clarity and relevance. The questions were modified accordingly following this process.

With the pre-established interview guide questions, the primary investigator (author 1) conducted the face-to-face interviews after securing informed written consent. Audio recording and memo writing were part of data collection during the interviews which were used as supplementary material and for reflection and interpretation of the interview data (Holloway & Wheeler, 2010). After achieving data saturation four more participants were interviewed for member checking for the iteration and cross-validation of the main themes (Birt et al., 2016). The checking of the accuracy of transcripts was performed by bilingual psychiatric nurses in the transcription and translation processes.

Data analysis

The data were thematically analysed using an inductive approach through concurrent and constant comparison after each interview. Thematic analysis is most appropriate to identify, analyse and describe patterns of meaning that ultimately highlight the most salient constellations of meanings present in the data set. Thematic analysis is best suited for "explaining the specific nature of a given group's conceptualization of the phenomenon under study" (Joffe, 2012, p. 212) making it the best fit for the current study.

Audio-recorded data in Amharic (the local language) were transcribed into English for analysis. To check the accuracy of translation, the English transcripts were appraised by psychiatric nurses who had adequate fluency in both languages. After familiarization with the data, the primary author openly coded the transcripts into two broad groups; one group encompassed the journey to conventional psychiatric care settings, and another group contained codes about conceptualizations of recovery. Codes having close/similar concepts were collated to give categories which were then formed into themes. Another researcher (author 5) checked the appropriateness of the codes and themes generated by looking at the quotations for each code and when necessary, referring to the whole transcripts. The themes were reviewed and tightened through iteration of codes from different interviewees (Braun & Clarke, 2006). Three other researchers (authors 2 to 4) verified the themes by looking at the supporting quotations.

Rigour

The rigour of the study and hence the findings were verified by iteration of codes and categories from participants' original transcribed data and finally by cross-checking with other research team members. Rigour was ensured by recruiting participants from different recovery levels,

collecting data until saturation, and persistently taking memos/field notes throughout the interviews and analysis (Holloway & Wheeler, 2010). Being reflexive in each of research stage is the main activity to be considered to enhance the confirmability (Seale, 2011). Interviews were conducted in a private room where interviewees sought their routine psychiatric follow-up care. In terms of reflexivity, assumptions that researchers brought to the study could have an impact on data collection, analysis, and interpretations. In addition, the research paradigm applied in this study, post-positivism, accepts that the value, experience, and background knowledge of the primary researcher (author 1, final year, male PhD student at the time of data collection, share the sociocultural background of participants) can influence the data collection, analysis, and interpretations. However, in the final data analysis and interpretation process, other researchers (authors 2–5) who are from different cultures and settings, but who are in the field of mental health have been involved, adding more perspectives to the interpretations of the findings of this study and hence could enhance the rigour of the study. The study has been reported in accordance with the Consolidated criteria for reporting qualitative research (COREQ) guidelines.

TABLE 1 Descriptions of qualitative study participants.

	Category	Freq (%)
Sex	Male	12 (63.16)
	Female	7 (35.84)
Residence	Urban	16 (84.21)
	Rural	3 (15.79)
Psychiatric diagnosis	Schizophrenia	10 (52.36)
	Schizoaffective	6 (31.58)
	Delusional disorder	1 (5.26)
	Schizophreniform	1 (5.26)
	Substance induced psychosis	1 (5.26)
Age in years	18–24	8
	25–35	7
	≥38	5
	Median	**Range**
Duration of untreated psychosis in months	3	1–48
Duration with illness in months	12	3–48

RESULTS

A total of 19 individuals with recent-onset psychosis were interviewed to share their journey to and through conventional psychiatric care for their mental illness and their understanding and perception of recovery. The majority were diagnosed with schizophrenia (52.6%) per the DSM-5 criteria as recorded in service users' charts. The sociodemographic and clinical characteristics of the participants are presented in Table 1.

Journey to and through conventional psychiatric care

Participants shared their long and complicated journeys to psychiatric healthcare, these included facing challenges to initiate, adhere and engage in psychiatric treatment and having frequent treatment interruptions. The diagrammatic presentation of findings is presented in Figure 1.

Most participants mentioned that their first attempt to manage their illness was either at spiritual or traditional healing sites.

A male participant stated that,

> They (his parents) took me to different places for prayers and traditional healings, traditional healers gave me things to smell, smoke and tie on my neck … trying all these for about a year or longer, I did not get any benefit … and then they brought me here.[F5]

Some were even referred by traditional healing practitioners. A young man said

> the traditional healer said I am cursed …and have mental distress … he gave me a medicine (traditional) for the curs but for the mental distress he said I have to be treated in hospital for six months … And taking his advice I came here (hospital).[G3]

However, a few reported that their first visited treatment sites were conventional healthcare settings.

Most participants shared that they arrived at the psychiatric hospital after trying the spiritual and/or traditional healing site for varying periods of time. They stated that after having treatment in the health care settings they had symptomatic improvements. However, they also discontinued psychiatric treatment for various reasons.

One of the participants stated that

> … in the holy water I did not get that much improvement; they (parents) brought me here and there was a lot of improvement … but … I discontinued taking the pills for about a year but all the problems came again.[G6]

The reasons for treatment interruption were different for different participants. Participants who interrupted treatment often went back to the spiritual healing sites (to be treated with holy water) again aspiring for a cure and spiritual harmony.

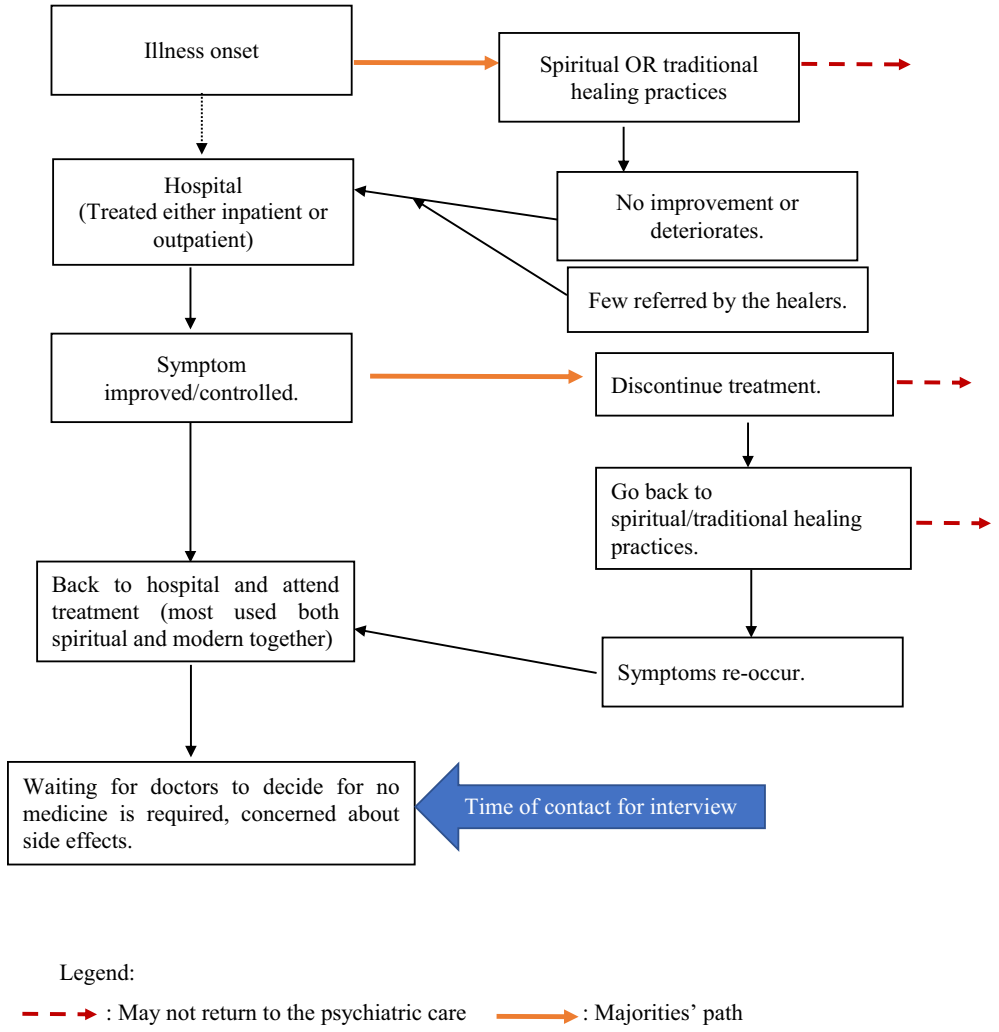

FIGURE 1 Journey to and through conventional care settings for psychotic illness. - - →: May not return to the psychiatric care ——→: Majorities' path.

Unfortunately, many participants explained that their psychotic symptoms re-emerged as antipsychotic treatment was discontinued, and therefore, they returned to the hospital for help. A participant said that

> … after … I refused to take them (the pills) … they (family members) took me to the holy water … but after few months there I got sick again … and came back here.

An important point that must be noted here is that participants in this study were those who were on psychiatric treatment and were engaged in follow-up, at least during the time of the interviews. It is also worth noting that many others might stay longer in traditional healing sites or may never initiate treatment for their mental illness at psychiatric hospitals. At the time of the interviews, most of the participants were attending both the spiritual and conventional/western treatment modalities. Another vital issue to accentuate is that participants in this study had been waiting for their "doctors" (psychiatric care providers) to either reduce their dose of medication or to declare that "they have completed their treatment".

A woman stated that

> I am having too many pills … for how long should I keep taking the pills, it has been three years since I started taking it ….[F2]

Another male participant also said that "the doctor also told me … she (the psychiatrist) will reduce the doses of the pills".[F4] Another participant also mentioned that he was looking forward to complete the treatment; "I wish to complete my treatment as soon as possible".[F3] This might be an issue of insight into the nature of illness, treatment, and recovery which would potentially affect hope, motivation, and subjective recovery in later days.

Conceptualization of recovery

The service users' conceptualizations of subjective recovery from recent-onset psychosis were summarized into four main themes, "domination over the disturbance of the illness", "complete medical treatment course and stay normal", "staying active in life with optimal functioning", and "reconcile and rebuild".

Domination over the disturbance of the illness

Psychiatric service users with recent-onset psychosis described that they would perceive themselves as recovered if they dominated the disturbances of the symptoms they had/were having. Participants perceived that recovery was not just being free from the illness but gaining the ability to live a life that was not devastated by the illness. Most service users vividly mentioned that being free from symptoms would be a clear indicator of their recovery. Despite participants having multiple psychotic symptoms, most of them mentioned only one or two major concerns, which they needed to get relief from and hence could declare their recovery is achieved.

A female participant placed most emphasis on her sleeping condition "… I will say I recovered if I am able to sleep well, able to get enough rest at night and stay awake in the daytime, like any other people".[G5]

Another male participant emphasized how his interaction with others was affected by his illness and he considered overcoming this problem was one of his recovery indicators.

> …I used to have disturbed mood and quarrelling behaviour, I used to clash with family members, friends and co-workers, I used to be upset by the words … the way they spoke to me … but I am stable now … we (family members) are peaceful now … now things have changed … after I recovered, I even got married.[F1]

From this, it was also possible to expand his description that being free from the most disturbing symptom/s was the trigger to continue in the progress of recovery.

Service users also mentioned that it was not only being free from symptoms that could be considered as recovery, rather the capability to have control over the illness/symptoms and be able to live a life in a self-directed way. They stated that recovery is regaining the ability to suppress the aggressions and confusions which made them do something they perceived as being "wrong". A 38-year-old female stated that "I get annoyed when people saw me like this (she complained she had hairs on her face), I could not stand that feeling that is why I quit my work … I wish the treatment could help me to overcome this feeling …".[F2] This is about service users' own strength to suppress the symptoms that affected their behaviours and life.

Indeed, participants also clearly acknowledged that gaining insight/awareness into symptoms, behaviour and self was a central component of recovery. Interviewees stated that they considered themselves as recovered when they became aware of the problematic illness-related behaviours they had and therefore they could strive to suppress these behaviours.

Another 24-year-old female stated that

> …I will say I recovered if I am able to recognize my thoughts/behaviours … now I sometimes do not know what actions I did, I do not even recognize what I am speaking, they (her family) are telling me I am acting wrong … but I wish I recover soon and I am always aware of the words I am speaking and actions.[D4]

Certainly, interviewees defined their recovery not only from the experiences of illness perspective but also from the psychiatric/medical treatments they were having.

Complete antipsychotic treatment course and stay normal

Interviewees acknowledged the benefits of medicine (antipsychotics) for embarking on the journey of recovery. However, some participants stated that they should be able to live free from medicine to say they have recovered. To consider themselves as "recovered" they need to stay in control of themselves or to be free from symptoms irrespective of the medicine they were having. Interviewees were expecting to complete their treatment course (antipsychotics and other interventions) for their illness and stay healthy for the rest of their life, like others in their community.

This perception of the illness/psychosis and treatment for it could affect perceived recovery, and engagement in psychiatric care. It seems that participants conceptualized "recovery" as equivalent to "cure". Maybe, that is why some interviewees used the terms "normal" and "being like others" to describe their recovery.

A 27-year-old male made it clear that:

> … if I am free from it (sleeping problem, his main complaint) while only having the pills it means I am not recovered; to say I recover I should be able to sleep normal while not taking the pills.[G3]

Perhaps, the concern might not only be free from medicine but also being free from the side effects of these antipsychotic medicines. Participants clearly recognized the

multifaceted impacts of the antipsychotic medicines they were taking. Physical complaints like getting easily fatigued when engaging in routine activities, weight gain, sleepiness and even sexual dysfunction were mentioned as the side effects of the medicines.

A participant stated that

> I wish I could fall asleep, I wish I could get rest, but the medicine is not like that, it doesn't make you sleep and wake … it just keeps me staying on the bed, I always feel tired, but I could not fall asleep…. [G4]

Another female participant stated that:

> … but in the morning the medicine drowns me I always have difficulties to wake up on time and keep up with others since I started it.[D1]

Participants conceptualized recovery not only from symptoms, treatment and impact of medication but also from an optimistic perspective such as returning to premorbid wellness. A 26-year-old male interviewee demarcated his understanding of his recovery as: "…these were what I lost, and I get them back now, this is recovery for me".[F6] When he was saying "…I get them back …" he was referring to his mental, physical, social, employment and economic issues.

Many others stated that recovery is "being normal" or "being like others". Perhaps the concepts of "being normal" and "being like others" might need further study and elaboration, but in a crude way, participants were saying that recovery is regaining the premorbid wellness not only in terms of mental and physical health but in functioning.

Staying active in life with optimal functioning

Participants recognized that due to their illness they lost their job or interrupted their study. They found it difficult to spend months, or even years without something to work on. Indeed, many did not aspire to resume the job they used to do, rather they needed anything to work on which would be appropriate to their condition. It became apparent that most service users clearly recognized their health state had been altered and hence having something to stay active, whether this generated income or not, would be acceptable to consider themselves as recovered.

A 30-year-old man who worked in the merchant navy stated that:

> I used to work on a ship … you know staying on the ship for a long time is so boring, the life there is so lonely … demands physical effort, attention and agility but these are what I lost since I get the sickness … now I am trying to perform some activities inside the house like cleaning rooms, cooking …next, I will work as tailor that my father used to work.[F4]

These kinds of reports were not only about getting a job that was appropriate to their health condition, but it was also about self-awareness indicating the holistic nature of recovery. The individualistic and continuous nature of recovery has become clear in these interviews, some would consider themselves as recovered if they could engage in any work. They wanted to have a job appropriate to their condition "… I wish I have something (job/business) that keeps me busy that I can handle … I mean to get a job that demands no/less physical effort".[G2]

Others aspired to resume their premorbid occupation. A 26-year-old male participant stated that resuming the job that he used to do was his wish, perhaps suggesting this could be one of the criteria when defining his recovery.

> … during the disturbance, I quitted my job and came to my parents … I am now working in a small shop… but I have a plan to have my earlier job … I want to resume my job free from disturbance and live by myself ….[F1]

From his statement, it is also possible to depict that recovery is making progress towards the optimum level of functioning and autonomy.

Psychosis is a known disabling illness particularly in its acute phase. It is therefore understandable that individuals with psychosis identified independency in self-care and other main life activities as criterion to define their recovery. The need for independence was not actually limited to comfort for the self but also to ease the caring burden of their families.

A 23-year-old female was worrying about her parents:

> … I am old enough to live by myself, but I am a burden to my parents, they are too old, I should have helped/supported them, not them supported me.[D2]

The concept of independence extends to economic issues and is not limited to self-care. Participants mentioned that they were expected to perform their roles in the family and in the broader community. A 42-year-old husband mentioned that "I wish I could help my wife in generating income for the family".[F3] Role and social expectations may vary with age and gender. A 32-year-old divorced female clearly pointed out that her recovery would be defined by getting married again. "If I get better, I want to marry and wish to live like anyone else".[G6]

Generally, "staying active in life with optimal functioning" is designated for a broad concept ranging from a simple concept of "able to work to stay active" to a more

complicated one "meet others' expectations in performing roles". The purpose of being functional was not limited to having a job, rather it related to having anything to do that would help them to stay active in life. Being active in life and society would help service users recognize their situation/surroundings, which in turn could help them to reconcile with the realities they were having.

Reconcile and rebuild

The realities of the participants' lives were clearly altered following the onset of psychosis. Participants recognized this change and decided to move on in life with the new reality "live with psychosis". Some participants defined their recovery as accepting the new reality and working to build new lives, giving the theme "reconcile and rebuild".

Recovery from psychosis demands a critical readjustment of these vital components; it needs to reconcile with the new reality (altered health condition and situation) that affects almost everything. Service users clearly identified their recovery should be defined in terms of their acceptance and reconciliation to their new situations in general.

A 24-year-old female said:

> … I am able to recognize my thoughts/behaviours … I accepted myself, I am pleased what I am, I am also trying to share my experiences with others … I have good/positive thoughts/plans for my life … this is what I understand recovery is.[D4]

From this, it is possible to postulate that recovery is not only about the symptoms or functioning, rather it is also about making peace with the condition rather than struggling to rebound to the premorbid state. Recovery is accepting the new self, accepting others and others' views towards self, it is making harmony with the new reality.

Psychosis is a devastating illness that destroys the pillars of ones' life and this requires gaining hope and having courage, stamina and strength to rebuild a new life. Indeed, it became clear that the life to be reconstructed did not need to be the same as the life before the onset of the illness. Rather, emphasis was given to a life that has meaning and provides motivation for living and to have hope for a better future.

DISCUSSION

Mental health care service utilization for different types of mental health problems including severe mental illness (SMI) is unacceptably low in low-income countries with the worst level of utilization reported in Sub-Saharan Africa (Nicholas et al., 2022). A very low proportion of individuals with psychotic disorders seek psychiatric care from conventional/modern care settings, with many encountering a long journey with numerous hurdles. The current study clearly documented that individuals with recent-onset psychosis pass through several spiritual and traditional healing services to reach the conventional psychiatric care hospitals where these interviews were held. Despite this, the majority of those who started psychiatric treatment interrupted for several reasons (Temesgen et al., 2020). This could have impacted service users' mental and psychosocial health outcomes in multiple dimensions.

The long journey to conventional psychiatric care services and frequent interruptions may be related to service users' understanding of recovery and illness. Participants in the study conceptualized their recovery in terms of relief from psychotic symptoms, psychiatric treatment, improved functioning and reconciliation with their illness and life change due to the illness. Indeed, recovery from mental illness is multifaceted, incorporating the symptomatic, functional and psychosocial components (Anthony, 2000; Slade et al., 2012).

Previous studies documented that people with psychotic disorders often understood recovery differently, ranging from cure from the illness (Noiseux et al., 2009) to having a meaningful life (Shepherd et al., 2008). It was found that subjective recovery is an outcome to be achieved, a process towards a targeted outcome or efforts of overcoming illness-related disabilities (Temesgen et al., 2019). The conceptualizations of recovery from recent-onset psychosis by service users in the current study could be embedded within these broad ranges of recovery concepts.

Domination over the disturbance of psychosis

Individuals with recent-onset psychosis conceptualized their recovery as being able to dominate the disturbances of the mental illness they experienced. This is congruent with one of the domains of the recovery assessment scale (RAS), i.e., "mastering my illness" (Hancock et al., 2016). However, this domain has been modified as "no domination by symptoms" (He et al., 2021). Several previous Western studies also found similar conceptualizations. For example, Shepherd et al. (2008) and Noiseux et al. (2009) defined recovery in mental illness as staying in control of one's life which could also mean being able to dominate over the symptoms to have a controlled life. Individuals with psychosis identified important components of recovery such as, regaining control over the experience, and negotiation and acceptance of treatment (Windell et al., 2015). However, some interviewees in the current study also defined their recovery as being completely free from the symptoms and functioning impairments they had.

Finish course of treatment and stay normal

This perception of recovery could be related to service users' awareness about the nature of recent-onset

psychosis and their optimistic, perhaps unrealistic expectations of psychiatric treatment. Service users with psychotic illness in Hong Kong (Ng et al., 2008) and India (Mathew et al., 2023) also defined their recovery as being free from medication and have good and stable health. Other studies also found that participants defined their recovery as being able to live without the medicines (Norman et al., 2013; Windell & Norman, 2013). However, for the current study participants from Ethiopia, it was not only about being free from the antipsychotics, but it was also "finishing the course of treatment" which might indicate a lack of insight about the potential need to take medication over the long term and the differences between treatment for psychosis and treatments for short-lived infections which would be prescribed as a limited course. Perhaps, this perception could be one of the reasons that most service users interrupted their treatment, disengaged from the conventional psychiatric treatment service, and switched to other modalities, such as spiritual healing sites. There is no limited "course of treatment" to be completed for psychotic disorders (Harrow et al., 2012; Harrow & Jobe, 2007). Nevertheless, participants in the current study seemed to believe that their illness was something to be cured with a limited course of treatment. This idea could lead to unrealistic hope that most likely would influence treatment-seeking behaviour and could result in subsequent potentially unfavourable outcomes.

Stay active in life with optimal functioning

Psychotic disorders are known to affect functioning (Sumskis, 2013; Valencia et al., 2014; Whiteford et al., 2013). Individuals with psychosis do not only have impaired functioning, they also often have inactive lifestyles due to the impacts of the illness that are further exacerbated by the side effects of antipsychotics (Robson & Gray, 2007; Thongsai et al., 2016). Therefore, it is understandable that participants defined their recovery as staying active in their life with optimal functioning. Previous studies also found that being able to actively engage in the social and working environment was among the defining characteristics of subjective recovery (Connell et al., 2015; Eisenstadt et al., 2012; Wilken, 2007) which could help them to regain self-reliance, confidence and independence (Habtamu et al., 2018; Menezes et al., 2009).

The potential difference between previous studies conducted in Western countries and in the current study could relate to the contextual meaning of "functioning". Participants in the current study were not selective for the kind of activity (i.e., paid or unpaid) they wanted to engage in. The main concept of functioning in the current study was for the activity/job to be appropriate to their current mental and physical health conditions so that could stay active and regain some level of independence. These ideas could be different from previous studies as participants from Western countries emphasized that they wanted to be engaged in an occupation and become financially independent (Bourdeau et al., 2015; Jaaskelainen et al., 2013). This could be due to cultural variations; the culture in the current study area might not have strict definitions for a job, it may consider any activity such as assisting family members in cleaning, cooking or farming as a job/functioning, no matter whether it directly generates income or not. The other important point to highlight is that participants in the current study felt they needed to stay well and active in daily functioning, both for themselves and important others. This perceived need to reduce or share the family burden might reflect the collective nature of the society in which they live. This could also be among the reasons for the higher reported recovery levels in low-income societies (Jaaskelainen et al., 2013). The need to stay active for others' benefit could have also helped them to properly readjust with the changed reality following the experience of psychosis.

Reconcile and rebuild

The other main premise that participants used to outline their recovery was reconciling with the changed reality and rebuilding a new identity, functioning and life. It has been emphasized that recovery is a journey of self-discovery to personal growth (Deegan, 1996; Slade et al., 2008). It is pertinent that the journey of self-discovery should be accompanied by reconciling with the new realities that individuals with psychosis faced and rebuilding new hope and ways of living (Davidson et al., 2008). A systematic review synthesized the definitions of subjective recovery as multidimensional including generating hope and belief of recovery (Wilken, 2007). Another individual study among Canadians with recent-onset psychosis also found that reconciling the meaning of the illness experience was among the defining components of subjective recovery (Windell et al., 2015). The findings of the current study generally seem to be in accordance with earlier views of recovery as an ever-changing journey of goal readjustment, that involves developing new meaning and purpose in life and self-optimization (Anthony, 2000; Davidson et al., 2008).

The current study revealed that individuals with recent-onset psychosis go through a long journey to initiate conventional psychiatric treatment. Treatment initiation, engagement and adherence to psychiatric treatment were reported to be full of hurdles. In keeping with Nicholas et al.'s (2022) findings; the main reason for the current study participants' delayed treatment initiation and frequent disengagement from the conventional psychiatric care service was mostly related to beliefs about health, the treatment of psychiatric illness and perceptions of recovery. Besides, in accordance with Munson et al.'s (2012) framework for understanding mental health service utilization in younger people, unmet expectations from psychiatric care (such as not being supported

to achieve specific goals, obtain expected rewards, or develop into the person they would like to become) contribute towards disengagement from services. These findings highlight that clinicians should aim to identify service users' expectations of treatment at the first point of contact and collaboratively construct realistic recovery-focused goals to maximize engagement.

LIMITATIONS

Several study limitations need to be considered. Study participants were purposively selected from referral hospitals and thus might not represent broader populations in primary care settings and/or religious healing services. Individuals who disengaged from these hospitals were unable to be contacted, thus not being represented. Although efforts were made to ensure the equivalency of meaning when translating from Amharic to English, it is possible that some meanings might not be captured. This study considered perspectives of individuals with recent-onset psychosis only; however, the findings might have been richer if their caregivers were included in the interviews.

CONCLUSIONS

Psychiatric service users in conventional healthcare settings could pass through a long family-accompanied journey, full of interruptions and uncertainties to stay engaged with their treatment. Clearly reflected in their journey to psychiatric care, service users with recent-onset-psychosis conceptualized their recovery ranging from a simple concept of being free from the illness symptoms to a more complex one such as reconciling with the illness and building hope for the future.

IMPLICATIONS FOR PRACTICE AND RESEARCH

Having found different delays in psychiatric care initiation and disengagement from psychiatric services, future research should explore the reason/s for delayed presentation to psychiatric care settings and high disengagement rates. Stakeholders need to formulate contextualized interventions to enhance engagement by enriching service users' insight into the enduring nature of psychiatric illnesses and their treatment. Care providers need to be cognizant that many individuals with psychotic illnesses visit psychiatric care settings after trying other care modalities. This can result in significant periods of untreated psychosis and may lead to alternating between conventional and traditional/spiritual healing sites. Psychiatric care providers and stakeholders need to acknowledge the very individualistic concept of recovery; thus, the goals of treatment need to be personalized rather than targeting only treatment adherence and symptom control. Mental health nurses should consider engaging service users and significant family members in conversations about their treatment preferences and beliefs in traditional/spiritual healing. Efforts should be made to ensure that service users perceive that they do not need to disengage from psychiatric services if they want to visit traditional/spiritual healing sites and that the two services can coexist and work together to support personal recovery and achievements of life goals.

AUTHOR CONTRIBUTIONS

Worku Animaw Temesgen: Conception, participant recruitment, data collection, analysis and writeup; Wai Tong Chien: Conception, interview guide development, and writeup; Maritta Anneli Valimaki: Writeup and edits; Yan Li: Writeup and edits, Daniel Bressington: Conception, interview guide development, analysis and writeup.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data used to develope this manuscript are included in the manuscript itself OR details can be given on request to the pI.

ETHICAL APPROVAL

This study was approved by the Human Subjects Research Ethics Sub-Committee of The Hong Kong Polytechnic University (Ref No: HSEARS20170808001). The Amhara Public Health Institute (APHI) also granted ethical approval for the study to be conducted in Ethiopia (Ref No. APHI/01/771). Written informed consent to take part was obtained from individual participants. As an inclusion criterion, only those mentally competent individuals were recruited for this interview and hence they were eligible to give informed written consent to participate in this study.

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